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ABSTRACT

These three issues of the "Research Exchange" focus on how better to conduct disability research and disseminate research results. The first issue examines the topic of human subject/human research participant protection, with a focus on research funded through the National Institute on Disability and Rehabilitation Research (NIDRR). It provides answers to questions concerning U.S. Department of Education requirements for human subject/human research participant protection, information on Institutional Review Boards that review research activities to protect the rights and welfare of human subjects, information on the Association for Accreditation of Human Research Participant Protection Programs, and organizational policy statements on protecting participants in research. Resources on human research participant protection are provided. The second journal issue discusses how NIDRR grantees can increase access to disability research information in rural communities. Outreach strategies of the Research and Training Center on Rural Rehabilitation Services are described, and experiences from the lower Mississippi Delta states are discussed. Related resources on rural issues are listed. The final issue highlights examples of how several NIDRR grantees have worked with the media to disseminate disability research. Tips are provided for working with the press and resources are provided for developing virtual press rooms and press kits. Some articles include references. (CR)

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# The Research Exchange

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# The Protection of Human Participants in Research

The participation of human beings in research studies is necessary in order to achieve advances in medical and social/behavioral sciences. Such research is not risk-free, and investigators must identify and examine the potential risks to participants, weigh them against potential benefits, and share that information with the individuals recruited to voluntarily participate in the research. This issue of *The Research Exchange* examines the topic of human subject/human research participant protection, with a focus on the experiences of researchers funded through the National Institute on Disability and Rehabilitation Research (NIDRR).

Every NIDRR-funded research proposal requires assurances from grantees that the human subjects who participate in the research will have adequate protections from harm, or, that the research is exempt from the regulations. These assurances are intended to guarantee that all researchers will employ the highest ethical practices so that research participants receive maximum benefit with the least risk of harm. Researchers should view this as more than a funding requirement. Strategies for the protection of human subjects should be described in the research proposal, and the successful implementation of the procedures should be reported as part of the findings (R. Melia, personal communication, April 20, 2001).

## Human Subjects or Participants?

Human subjects is the term currently used in most legislation to describe the people who participate as subjects in a research study. In this issue of *The Research Exchange*, the NCDDR joins many organizations that embrace the use of the word *participants* in place of *subjects* (AAHRPP, 2001; APA, 2001; IOM, 2001; NBAC, 2001; White, in press). The Institute of Medicine, in its report *Preserving Public Trust*, points out that regulatory language differentiates the person being studied from the researchers and other investigators.

Use of the term "subjects" emphasizes the power difference and the need to protect vulnerable people. Other terms have been proposed, such as *respondents, partners, probands, volunteers,* and *patients* (IOM, 2001, p. 33).

The National Bioethics Advisory Commission uses the term "participant" as a more neutral word that identifies the person as different from researchers (NBAC, 2001). The National Institutes of Health "uses the term ***human participant*** to mean ***human subject,*** the term used in the

*continued on page 2*



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A Word from the Director

# Protecting Research Participants

All research activities, especially those funded through public monies, must protect participants from risk in the course of the research activity. Glaring research design problems have occurred in the recent past and have stimulated administrative procedures to safeguard individuals who participate in research studies. The Tuskegee Syphilis Study began in 1932 with 600 low-income African American males. Pursuant to a preconceived research design, 399 men infected with syphilis were monitored for 40 years.

Even though a proven cure, penicillin, became available during the course of the research study, no treatment was provided. As many as 100 people died from syphilis during the study. It was terminated in 1972 after the practices became known and publicized.

Clearly, the research design of the Tuskegee Syphilis Study did not take into consideration the notions of informed consent, maximizing potential benefits, and minimizing potential risks that today are the cornerstones of human research participant protection. It also did not benefit from review by an impartial panel to ensure that the design of the research study would not cause harm to those who might participate.

Today, review by a designated board prior to initiating research efforts involving human subjects is accepted procedure in America's colleges, universities, medical schools, and other institutions conducting such research with partial or total support from Federal funds. A variety of strategies have been developed to ensure that human subjects interested in participating in research studies understand what consequences or impact their involvement may have during the course of the study and into the future.

It is incumbent upon researchers to understand the requirements associated with safeguarding human subjects in research studies. This issue of *The Research Exchange* is designed to provide useful information and resources for developing human subject safeguard procedures and guidelines in research proposals. Especially important in conducting NIDRR-sponsored research activities involving human subjects is awareness of what safeguards are needed when people with disabilities are research participants. Informational resources and contacts are available to researchers that may have particular questions regarding human subject protections. The staff of the NCDDR hopes this issue is helpful in informing and directing researchers to appropriate resources in this area.

*John D. Westbrook, Ph.D.*
*Director, NCDDR*

The Protection of Human Participants in Research, *continued from page 1*

federal regulations" in its online tutorial, *Human Participant Protections Education for Research Teams* (NIH, 2002).

The Association for the Accreditation of Human Research Protection Programs (AAHRPP) was created "to ensure that scientific research can continue to grow and flourish under conditions in which the best interests of research participants will be protected" (AAHRPP, 2001). There is a definite trend toward use of a more humanizing term such as "participants" instead of "subjects."

## Historical Foundations

The need for special efforts to protect research participants became clear as evidence emerged over the past 60 years of numerous cases of abuse of research study participants, with sometimes devastating and even lethal consequences. Vulnerable populations, including people with disabilities, were often treated with disrespect as unwitting and uninformed 'volunteers.'

Three primary documents provide the foundation for efforts to protect human beings who participate in research. These are the *Nuremberg Code*, the *Declaration of Helsinki*, and the *Belmont Report*.

The *Nuremberg Code* is a statement on medical ethics that was issued in 1947 after the trial of 23 medical doctors accused of atrocities committed during the Nazi era in Europe in World War II. These "basic principles must be observed in order to satisfy moral, ethical and legal concepts" in permissible medical experiments. Voluntary participation and informed consent of the research participant is the first of ten items in the *Nuremberg Code* (United States Holocaust Memorial Museum, n.d.)

The *Declaration of Helsinki* on Ethical Principles for Medical Research Involving Human Subjects was adopted by the World Medical Association (WMA) in its 18th General Assembly in Helsinki, Finland in 1964. It has been amended six times, most recently in October 2000 at the 52nd General Assembly held in Edinburgh, Scotland. The *Declaration* presents basic principles for all medical research and additional principles for medical research combined with medical care. In the latest amendments some controversy has emerged regarding the use of placebos (WMA, 2000).

*The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research* was



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## What Current Federal Rules Govern the Protection of Human Subjects?

The ED is one of 17 Federal agencies that have adopted the "Common Rule," or *Federal Policy for the Protection of Human Subjects*. Initially developed by the HHS, the *Common Rule*, 45 CFR 46, was published in the *Federal Register* on June 18, 1991 (56 FR 28003) and became effective on August 19, 1991. Each agency that has adopted the *Common Rule* has its own set of regulations that reflect the HHS-developed legislation.

The *Common Rule* requires assurances from research institutions that they will:

- comply with all regulations
- obtain informed consent and maintain documentation of the consent and
- present the research for review by an independent IRB. Guidance on IRB membership and record keeping is also specified in the legislation, although rules on IRB operation and decision-making are not addressed.

The ED regulations codifying the *Common Rule* are found in 34 CFR 97. This refers to Title 34 of the Code of Federal Regulations, Part 97 — Protection Of Human Subjects, Subpart A — Basic ED Policy for the Protection of Human Research Subjects, and Subpart D — Additional ED Protections for Children Who Are Subjects in Research. These regulations are available online:
**http://www.ed.gov/offices/OCFO/humansub/part97.html**

For NIDRR-funded projects, there are additional requirements in 34 CFR 350 and 34 CFR 356 to ensure protection of children with disabilities and individuals with mental disabilities. These regulations are found at:
**http://www.ed.gov/offices/OCFO/humansub/34cfr350.html**

## Federal Government Resources on Human Subjects Protection

The U.S. Department of Education (ED) has developed a Web page with links to important information related to Human Subjects Protection. The page provides general information, regulations, guidance and educational materials, assurance information and more, with links to pertinent documents:
**http://www.ed.gov/offices/OCFO/humansub.html**

The U.S. Department of Health and Human Services (HHS) established the Office for Human Research Protections (OHRP) in June, 2000, to coordinate research efforts throughout HHS, including the National Institutes of Health (NIH). The OHRP registers Institutional Review Boards (IRBs) and negotiates Federalwide Assurances of Protection for Human Subjects (FWA) with various research entities. The process can be initiated online. The OHRP Web site provides links to extensive resource materials, guidebooks, forms, training, and other informational links:
**http://ohrp.osophs.dhhs.gov/index.html**

Beginning October 1, 2000, the NIH implemented a policy requiring education on the protection of human research participants for all investigators submitting NIH applications for grants or proposals for contracts, or receiving new or non-competing awards for research involving human subjects. The policy announcement is found at:
**http://grants.nih.gov/grants/guide/notice-files/NOT-OD-00-039.html**

*Frequently Asked Questions* about the education requirement are found at this location:
**http://grants.nih.gov/grants/policy/hs_educ_faq.htm**

*Human Participant Protections Education for Research Teams* is an online tutorial developed by NIH to help non-NIH personnel to comply with this policy. Visit:
**http://cme.nci.nih.gov/**

A number of universities and research institutions have made online courses available to their researchers and other interested individuals. Some of these are listed in the "Selected university-based online tutorials" on page 19 of this issue.

developed by the National Commission for the Protection of Subjects of Biomedical and Behavioral Research (1979). The Commission was established under the National Research Act of 1974 (Protection of Human Subjects of Biomedical & Behavioral Research, Public Law 93-348). Its charge was "to identify the basic ethical principles that should underlie the conduct of biomedical and behavioral research involving human subjects and to develop guidelines which should be followed to assure that such research is conducted in accordance with those principles." These fundamental ethical principles are respect for persons, beneficience, and justice.

- *Respect for persons* involves recognizing the personal dignity and autonomy of individuals, and offering special protection for persons with diminished autonomy. This principle is implemented in the area of informed consent, where sufficient information, comprehension, and choice to volunteer must be present.
- *Beneficence* entails an obligation to protect persons from harm by maximizing anticipated benefits and minimizing possible risks of harm. This principle is applied in identifying individual risks and potential benefits, as well as those of society at large, and assessing and weighing the alternatives.


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- *Justice* requires that the benefits and burdens of research be distributed fairly. The application of this principle is seen in the fair selection of research participants (National Commission, 1979).

*The Belmont Report* was written after more than four years of deliberation, and it still stands today as the foundation of Federal policy on protecting human participants in research.

## Vulnerable Populations

The national and international regulations and guidelines identify many groups as potentially vulnerable to being exploited in research. Some of these groups include: women, children and minors, fetuses, people with cognitive impairments, prisoners, traumatized and comatose patients, terminally ill patients, elderly/aged patients, people from diverse ethnic and cultural backgrounds, students, employees, people with disabilities, and people who are economically disadvantaged. Special considerations must ensure these groups are protected in research. Modifications may be required in recruitment, informed consent, and in the study procedures to meet the needs of participants who are members of vulnerable groups. Care must also be taken not to exclude participants due to vulnerable status. This would fail to respect an individual's autonomy and right to volunteer, if he or she should choose to do so.

## Conflict of Interest

Drug company support of research institutions, specific financing of research, incentives for doctors and researchers are all pieces of the research puzzle. A *Conference on Human Subject Protection and Financial Conflict of Interest* was held in August 2000, sponsored by the U.S. Department of Health and Human Services (HHS).

The purpose was to discuss regulatory requirements and guidance and to provide a forum for presentations of current approaches to deal with real and potential financial conflicts of interest at the institutional, Institutional Review Board (IRB), and clinical investigator levels. Information about the conference can be found at: **http://ohrp.osophs.dhhs.gov/coi/index.htm**

Hiring researchers as consultants, researcher ownership of company stocks, company donations to research institutions, and sponsorship of studies all contribute to the issue of conflict of interest. IRBs must be aware of a researcher's relationship to a company with an interest in the results of the research in order to make a decision about the study.

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# The View from the U.S. Department of Education: *Questions & Answers*

Many NIDRR grantees have questions about grant proposal requirements for human subjects protection, and they may not be sure where to find answers. One person who can share information is Hélène Deramond, the ED's Protection of Human Subjects Coordinator. Ms. Deramond works in the Grants Policy and Oversight Staff, the office responsible for administering the ED's human subjects regulation.

Dr. Richard Melia, Director of the Research Sciences Division of the National Institute on Disability and Rehabilitation Research (NIDRR), is another knowledgeable resource person.

Ms. Deramond and Dr. Melia collaborated to provide answers to several questions posed by NIDRR grantees, regarding human research participant protection.

**1. Can you please identify any substantial differences in the Department of Education (ED) requirements for human subject/human research participant protection compared with the requirements of the Department of Health and Human Services (HHS), National Institutes of Health (NIH), etc.? Are there differences that researchers need to be aware of to ensure they are in compliance?**

There are no significant differences between the ED and the HHS/NIH requirements. The reason is that, with few exceptions, ED modeled its policies and procedures after the HHS/NIH policies and procedures, and we have continued to do so. For example, we recently revised question 12 of our ED 424 grant application to drop the "IRB approval date" entry to parallel the same change in the HHS PHS 398 grant application form. This made sense since as a matter of policy, ED never had required that the IRB approval date be provided with the application.

There is one additional requirement that National Institute on Disability and Rehabilitation Research (NIDRR) grantees need to be aware of. The NIDRR regulations at 34 CFR 350.4 and 356.3 impose additional Institutional Review Board (IRB) membership requirements. When an IRB purposefully requires inclusion of children with disabilities or individuals with mental disabilities as research participants, the IRB must include at least one person primarily concerned with the welfare of these research subjects. ED requires that the IRB approval for such projects assure that the requirement was met.

**2. What is the difference between the Multiple Project Assurance (MPA) and the Single Project Assurance (SPA), and how does one know which is more appropriate to use?**

The assurance required by the regulation is the document that formally acknowledges an organization's intent to comply with the *Common Rule for the Protection of Human Subjects*.

Prior to November 2000, when HHS introduced the Federalwide Assurance (FWA), the two major assurance documents were the MPA and the SPA. Typically, only large institutions such as research universities that had a track record with HHS qualified for the MPA. Since HHS issued the MPA for multi-year periods, an institution that had an MPA did not have to submit an assurance for each and every research project in which it was involved either as the grantee or as a collaborating institution. The other advantage of the MPA was that it was valid not only for HHS-funded research but also for other Federally funded research, including ED-funded research.

Many institutions did not qualify for an MPA, typically because they had received few HHS awards for human subjects research. These institutions were required to submit SPAs for each nonexempt research project in which they were involved. If they were involved in an HHS-awarded research project, they would submit an SPA to HHS for approval. If they were involved in an ED-awarded project, they would submit an SPA to ED for approval.

HHS introduced the FWA late in 2000. Unlike the MPA, the FWA is available to any institution that applies for it. Just like the MPA, it is good for several years



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for multiple research projects, and ED and other Federal agencies accept it. Shortly after HHS introduced the FWA, if an institution did not have an HHS-approved MPA, ED gave the institution the option of applying for the FWA or of submitting an SPA to ED for approval. Currently, ED is requesting that institutions apply for the FWA. Our goal is to phase out the ED SPA just as HHS is phasing out the HHS SPA. (HHS is also phasing out the MPA. As MPAs expire, institutions will apply for the FWA.) We believe it is in the best interest of institutions to apply for the FWA since having the FWA means that they do not need to file a separate assurance for each project. The HHS web site address for the FWA is **http://ohrp.osophs.dhhs.gov/irbasur.htm**

**3. What other type of Assurance, if any, is acceptable to ED (other than the above referenced MPA & SPA)?**

We currently accept the FWA and the MPA. We are phasing out the SPA. We also have the Independent Investigator Agreement (IIA) for researchers who are not affiliated with an institution. Primarily researchers who obtain NIDRR fellowships use this IIA.

**4. Does (or will) ED accept the FWA issued by the HHS Office for Human Research Protections (OHRP), in place of the MPA or the SPA? Will the FWA replace either or both of these assurances?**

Yes, ED accepts the FWA. In fact, we are phasing out the SPA and encouraging our grantees and contractors to apply for the FWA. *See answer to # 2, on page 5.*

**5. Does the researcher need to obtain any type of official approval document from ED related to human subject/human research participant protection, in addition to approval from his/her institution's IRB?**

Except in unusual circumstances, ED will not make the award if the researcher's institution has not complied with ED's request for assurances and IRB approvals. When the institution has complied with the requirements, the grant award notification is the official ED approval document. The award notification includes the HS1 attachment, Continuing IRB Reviews, if nonexempt research activities will be conducted. HS1 essentially instructs the institution to send the annual IRB approvals to the funding office, e.g., NIDRR.

In unusual circumstances, for example at the end of the fiscal year, ED may make an award before the applicant has complied with ED's request for assurances and IRB approvals. In these situations, also, the grant award notification is the official ED approval document but it is a conditional approval. The award notification includes the HS3 attachment, Assurances and Initial IRB Certifications. HS3 notifies the institution that the nonexempt research activities cannot be initiated until ED receives the requested assurances and IRB approvals.

The Grants Policy and Oversight Staff, the office where ED's human subjects staff is housed, does not have a formal mechanism to notify the researcher that ED has received all the requested documents. Rather, GPOS notifies the funding office that the project is cleared when all the documents are in. Even though there is no formal mechanism, however, there frequently is informal communication between the researcher and the human subjects staff. Researchers should feel free to contact GPOS to verify that GPOS has received their paperwork. Once GPOS has notified the funding office that a project is cleared, it's up to the funding office to make the award.

To put all this in perspective, here is a brief description of how the process works in ED. When an application is selected or recommended for funding, the program office, e.g., NIDRR, sends the application to the human subjects protection coordinator in GPOS if it believes that the research will involve nonexempt human subjects research. GPOS then contacts the Project Director to request any needed assurances and IRB approvals. The applicant has 30 days to comply. In some cases, there is no need for GPOS to contact the Project Director because the institutions already have assurances and they have documented the IRB approvals. When the applicant has complied with all the requirements, GPOS notifies the funding office by e-mail that the project is cleared.

Multi-year projects require annual IRB approvals, and the funding office cannot make the continuation award if the institution has not sent NIDRR the annual approvals. Project Directors should be sure that this requirement does not fall through the cracks.

**6. When projects have a focus that is so different — a Dissemination and Utilization (D&U) proposal, for instance — it seems some of the required paperwork is not appropriate for that type of project. Does ED have any provisions for this, to avoid having to ask for exceptions, reviews and separate decisions?**

If a D&U project does not involve human subjects research, ED simply does not require assurances and IRB approvals. Often, a D&U project includes research activities such as consumer focus groups, surveys, or site reviews. Some of these activities could well be nonexempt. It is very important that applicants complete the six-point (now seven-point[1]) narrative attachment on Protection of Human Research Subjects in such circumstances. For example, a D&U project on substance abuse rehabilitation interventions may have focus groups where protecting

[1] The seventh point, which was recently added in the revised ED 424 instructions, deals with the involvement or role of any collaborating sites. The revised ED 424 is at **http://www.ed.gov/offices/OCFO/grants/appforms/ed424.pdf**



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the privacy of participants and the confidentiality of the information would be addressed in the narrative.

**7. In collaborative projects, should researchers seek review and approval from the IRBs of all participating institutions or just to the IRB of the primary recipient of funding for that particular project? How should ED be informed of this (what documentation would be required from the researcher's institution as well as the other participating institutions)?**

The primary recipient needs IRB approval for the project as a whole and for any discrete project in which it is directly involved. The collaborating institutions need IRB approval as well and we hold the primary grantee responsible for obtaining and sending those IRB approvals to ED. However, 34 CFR 97.114, allows an institution participating in a cooperative project to enter into a joint review agreement, rely upon the review of another qualified IRB, or make similar arrangements to avoid duplication of efforts. The primary recipient should first contact ED to discuss these arrangements.

**8. From ED's perspective, are there any problems related to Human Subjects/Human Research Participants' Protection that typically seem to be observed, that you'd like for researchers to be aware of so they could address/avoid them?**

From the perspective of the human subjects protection coordinator, the problems have been primarily technical ones. The human subjects narrative is sometimes missing from the application. We have recently revised the ED 424 instructions to hopefully make the requirement for the narrative more evident. We have also made more explicit the need to provide information in the narrative about the role of any collaborating sites in the research, because this aspect of the research is sometimes not spelled out as clearly as it might be.

Another sticking point is the time it takes for some institutions to obtain their IRB approvals. This is an area over which researchers may have little control. Our advice, however, is that they become familiar with their institution's IRB approval process so that they can submit the required paperwork to their IRB offices as soon as the human subjects protection coordinator contacts them. It would also be helpful if researchers would keep ED advised of anticipated delays in obtaining the IRB approval.

**9. In general, is ED comfortable with the level of protection provided to human subjects/human research participants in research proposals (especially those submitted to NIDRR)?**

While it is difficult to generalize, we believe that ED applicants are more attentive to the protection of research participants in their applications than they were several years ago when ED first implemented the regulations. More applications now include the narrative, and the narratives are more detailed than they were at the beginning.

More importantly, we know that the sensitivity of NIDRR grantees has been heightened because (1) ED now has a process in place to implement the regulation and (2) NIDRR has incorporated review of human participant protections in its program reviews of grantees, with particular attention to the informed consent process. An unanticipated outcome of increased focus in program reviews and NIDRR monitoring of human subject protection activities has been identification of "best practices" by NIDRR grantees in research activities involving human subjects. For example, program reviews of NIDRR Traumatic Brain Injury (TBI) model system projects have identified simplified consent forms and procedures for obtaining human subject agreements from persons with significant cognitive impairment due to TBI, or from their representatives as appropriate. In such instances, the "best practices" can be shared with other projects to improve their human research participant processes and perhaps increase recruitment and participation of research subjects.

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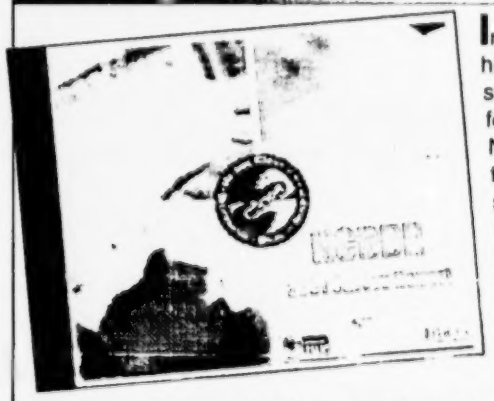
## NCDDR Survey 2001



In this report, major findings are highlighted based on consumer, stakeholder, and NIDRR grantee feedback. Findings from the annual NCDDR investigations are reported to provide D & U insights and suggestions that the NCDDR and other NIDRR grantees can most effectively and efficiently employ in conducting D & U to consumers and targeted groups.

On-line: **http://www.ncddr.org/du/products/survey2001/**



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# Institutional Review Boards

## Overview

The cornerstone of protection for human research participants is an independent Institutional Review Board (IRB). The purpose of the IRB is to review research activities at an institution with the focus of protecting the rights and welfare of human subjects recruited to participate in those research activities. The IRB is authorized to approve, require changes, or disapprove all research activities that it reviews. Officials at an institution may disapprove a project that has been approved by an IRB, however, they may not approve research that has been disapproved by the IRB.

Institutions may have their own IRB, may use the IRB of a cooperating agency, or may use a commercial IRB. In some cases more than one IRB may exist at an organization, based on the amount and variety of research. Often separate IRBs review clinical/biomedical research, and social/behavioral research.

Specific areas of concern to the IRB are informed consent, measuring the risks and benefits of the proposed research, and recruitment of subjects for research. These are described in the introduction of the HHS' *IRB Guidebook*:

> First, subjects must be given sufficient information on which to decide whether or not to participate, including the research procedures, their purposes, risks and anticipated benefits, alternative procedures (where therapy is involved), and a statement offering the subject the opportunity to ask questions and to withdraw at any time from the research.
>
> Second, subjects must be able to comprehend the information that is given to them. The presentation of information must be adapted to the subject's capacity to understand it. Finally, consent to participate must be voluntarily given. The conditions under which an agreement to participate is made must be free from coercion and undue influence. IRBs should be especially sensitive to these factors when particularly vulnerable subjects are involved.
>
> Closely related to the principle of beneficence (maximizing anticipated benefits and minimizing possible risks of harm), risk/benefit assessments "are concerned with the probabilities and magnitudes of possible harms and anticipated benefits."
>
> With respect to their status as individuals, subjects should not be selected either because they are favored by the researcher or because they are held in disdain (e.g., involving "undesirable" persons in risky research).

[From the Introduction to the IRB Guidebook available on the OHRP Website: **http://ohrp.osophs.dhhs.gov/irb/irb_introduction.htm**]

## Q & A with IRB Members

Representatives of two IRBs were interviewed to learn their perceptions of current research presented to their Boards, and special issues or concerns. Both IRBs are located at major universities sponsoring NIDRR-funded research. Following are questions and the IRB member responses.

**What are some of the primary concerns IRB members have about the research proposals they review?**

**IRB 1:** Although all research studies have importance, many are exempt or deal with research issues that have less risk. Those projects that deal with vulnerable populations are of more concern. In these cases, the IRB requests details about recruitment and selection of participants to ensure they are not included or excluded inappropriately, and about the informed consent process. These projects are always considered by the full board at their monthly meeting, while lower-risk studies may go through the expedited process with review by a subset of IRB members.

**IRB 2:** A current issue of concern is data from secondary subjects. If you are interviewing people who have given their consent, and you ask questions about other people they associate with, do you need to get the consent of those people? There was a case where a family member sued an IRB — and won — when information was revealed about the family member by a research participant during an interview. IRBs will be more conscientious of this type of research and the need to protect individuals who are not directly involved in the research study.

**There is a specific requirement for projects funded by NIDRR (Disability and Rehabilitation Research Projects and Centers Program; Research Fellowships) which states: "When an IRB reviews research that purposefully requires inclusion of children with disabilities or individuals with mental disabilities as research subjects, the IRB must include at least one person primarily concerned with the welfare of these research subjects" (34 CFR Part 350, Sec. 350.4; 34 CFR Part 356, Sec. 356.3). How does this IRB fulfill that requirement?**

**IRB 1:** The IRB members have varied backgrounds, including two medical doctors, a social worker, paralegal, and faculty from the fields of pharmacy, psychology, educational psychology, kinesiology, curriculum and instruction and nursing. If necessary, the IRB will ask faculty from other disciplines (for example, special education) or even outside consultants for their opinions. However, this very rarely happens.

**IRB 2:** All vulnerable populations need extra protection. For example, if the research involves prisoners, there should be a prison advocate. The IRB should include people knowledgeable about disabilities. In many cases, IRBs have negative perceptions of research with people with disabilities. The Chair of this IRB is a professional working with people with disabilities. The Board has a varied membership, including 25 percent

# Resources for Institutional Review Boards

**The IRB Forum** promotes the discussion of ethical, regulatory and policy concerns with human subjects research. The IRB Forum strives to create an atmosphere for open and respectful conversation about issues of mutual interest to the members.
**http://www.irbforum.org/**

IRB Home Pages: Over 50 university and independent IRB Web sites
**http://www.irbforum.org/links/links.php?category=5**

**American Association of University Professors (AAUP).** (2001). Protecting human beings: Institutional review board sand social science research. *Academe online, 87*(3).
**http://www.aaup.org/statements/Redbook/repirb.htm**

**American Psychological Society IRB Resources**
**http://www.psychologicalscience.org/newsresearch/irb/**

**Commercial Institutional Review Boards.** AdvaMed (Advanced Medical Technology Association) maintains a list of commercial institutional review boards (also known as independent IRBs) in the United States. Date of last revisions is provided.
**http://www.advamed.org/solutions/reviewboards.shtml**

**Gabriele, E.F.** (2000). Tending the ground of our being: The IRB and IRB administration in the biomedical research culture. *Journal of Research Administration, 1*(1), 17-21.

**Human Research Report (HRR)** is a monthly newsletter. Topics include: Compliance with IRB Regulations of NIH, FDA, DoD, DOE, etc.; Informed Consent; Research Ethics; Conflict of Interest; Scientific Misconduct; Subject and Patient Rights; Ways to Protect Researchers; Ways to Protect Research Institutions...and many more research compliance issues.
**http://www.humanresearchreport.com/**

**Institute of Medicine** (2000). *Institutional Review Boards and Health Services Research Data Privacy: A Workshop Summary*. Report of the Committee on the Role of Institutional Review Boards in Health Services Research Data Privacy Protection, Division of Health Services. Washington, DC: National Academy Press.
**http://books.nap.edu/books/NI000228/html/**

**IRB Navigator™** is a database and document management system for administration and support of Institutional Review Board activities. West Beach Software.
**http://www.wbeachsoftware.com/about.html**

***IRB: Ethics & Human Research*** is a journal devoted to philosophical and regulatory questions about biomedical and behavioral research with human subjects. The Hastings Center.
**http://www.thehastingscenter.org/publications.htm**

**Office of Inspector General.** (1998). *Institutional review boards: A time for reform*. Washington, DC: Dept. of Health and Human Services. OEI-01-97-00193.
**http://oig.hhs.gov/oei/reports/a276.pdf**

**PRO_IRB™** is a Microsoft Access-based Institutional Review Board Software Application providing productivity and compliance assurance tools for managing the Institutional Review Board process. ProIRB Plus, Inc.
**http://www.proirb.com/**

**Public Responsibility in Medicine and Research** (PRIM&R)
IRB Professional Certification Exam: FAQ
**http://www.primr.org/certification.html**

U.S. Department of Health and Human Services (DHHS)
Office for Human Research Protections (OHPR)
*Institutional Review Board Guidebook*
**http://ohrp.osophs.dhhs.gov/irb/irb_preface.htm**

U.S. Food and Drug Administration (FDA) Information Sheets
**http://www.fda.gov/oc/ohrt/irbs/**

21 CFR Part 56 - Institutional Review Boards
**http://www.fda.gov/oc/ohrt/irbs/appendixc.html**



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off-campus representatives, soon to be increased to 50 percent. These members include researchers from other local universities, personnel from the local schools, and other community members.

**About how many research proposals are reviewed in a typical 30-day period?**

**IRB 1:** At the regular monthly two-hour meeting, approximately 15 new full-board studies are reviewed. These are projects dealing with more risk and/or more vulnerable populations. During the average month, approximately one hundred exempt and lower-risk projects go through an expedited review. Additionally, there are minor changes to approved projects. The majority of projects reviewed by this IRB are social/behavioral, with fewer medical studies.

**IRB 2:** About 30 new applications are reviewed each month. In addition, there will be any number of expedited reviews that do not require the entire Board's approval, for renewals, changes in instruments, population studies, new staff members, and so on. Many studies are given an expedited review when the research represents minimal risk (the same as "everyday life"). The Chair determines whether or not a proposal is exempt. This IRB does not review medical studies.

**Overall, do most studies need changes or are most approved as presented?**

**IRB 1:** Yes, most studies do require some additional information or modifications, most often related to the informed consent process, or consent forms. As presented to the IRB, most studies are about "95 percent there" with some minor changes or additions often needed.

**IRB 2:** About ten percent of proposals with a full review go through with no changes suggested. The remaining 90 percent require some revisions. When changes are minor, they are passed by the Chair for approval. In rare cases major changes need to go before the entire Board again.

**What is your perception of the general feeling on the IRB regarding the quality of protections researchers are building into their proposed studies and how the process is working at this institution?**

**IRB 1:** Overall, the researchers are doing a good job. The idea of protecting research participants and the reason for an oversight process is understood and supported by both faculty and staff on this campus. In the future, we hope to make the process more seamless by using electronic capabilities.

**IRB 2:** Things are working well. The Board is experienced and the researchers are generally conscientious. It is important to note that the IRB decisions cannot be appealed or overridden. A project approved by the IRB regarding human participant protection may not be approved for funding for other reasons, but a project turned down by the IRB may not be approved by another entity at the university. If the IRB process is suspect, it can jeopardize all research at the institution.

**How long do people serve on the IRB, and are they reimbursed for their time?**

**IRB 1:** IRB members are asked for a three-year commitment, and often are asked to continue with additional three-year periods. There is at least one member on the current IRB who has served 12 years. Faculty and staff members serve on the IRB as part of their University employment, but members from outside the institution are provided a modest stipend for the time spent in monthly IRB meetings.

**IRB 2:** Did not respond.

**Has the University negotiated the new Federalwide Assurance (FWA)?**

**IRB 1:** Not at this time. We are working on the FWA, and it will replace the current MPA (Multiple Project Assurance).

**IRB 2:** The University has applied for the FWA to replace the MPA that is currently in effect.

**How do you handle cooperative studies that involve researchers and activities taking place through different institutions?**

**IRB 1:** These may be very complicated, and the IRB first looks at the complete protocol to determine what part the researcher is doing. If the role of the institution's researcher(s) is large within the study, the IRB may take the lead and try to coordinate the pieces that involve other institutions. Multiple IRB review can be very complex and sometimes requires delicate negotiations. In situations where the role of the local researcher is smaller, the IRB will share its approval with the other IRBs involved.

**IRB 2:** This IRB approves all projects the University's researchers are involved in. Often subcontractors will use the University's IRB if they have none. If data is analyzed in more than one place, then both IRBs need to approve.

**Does this institution participate in any research partnerships? For example, "MACRO" (Multicenter Academic Clinical Research Organization) joins five university medical centers to expedite the clinical trials process. One institution serves as the IRB of record for a specific study, and multiple approvals are not needed.**

**IRB 1:** We do not participate in a formal partnership, but in some cases certain researchers have established ongoing relationships with researchers at other institutions, and this IRB has a relationship with the other IRB as well.

**IRB 2:** There are some projects ongoing over several years with other well-known public universities around the country. However, the University does not participate in the type of partnership described.



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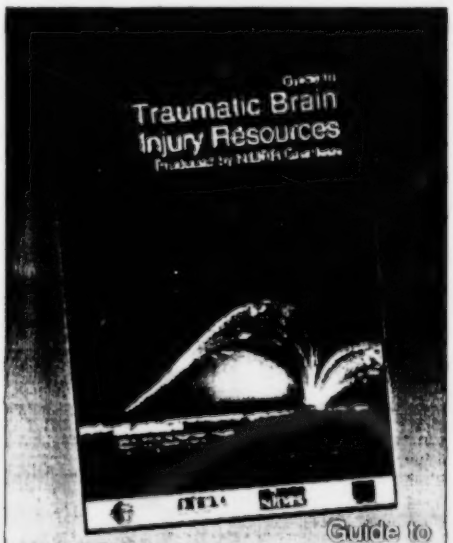
**Are you familiar with the new accreditation body, the Association for the Accreditation of Human Research Protection Programs? Is the University interested in pursing accreditation?**

**IRB 1:** Yes, and we think it is a great idea. The University plans to complete the accreditation process during 2002.

**IRB 2:** Accreditation is a good step toward improving protections. Although not a requirement, accreditation will imply greater scrutiny. Few IRBs have a perfect paperwork trail, so it will be important not to get hung up on paperwork and lose sight of the "WHY." That would only serve to destroy the credibility of the process.




This guide was developed to assist researchers, professionals, and people with disabilities in locating research training materials related to traumatic brain injury and disabilities that were developed by programs funded by the NIDRR.

On-line:
http://www.ncddr.org/du/products/tbiguide/index.html

# NIDRR Grantee Experiences with Human Research Participant Protection and IRBs

NCDDR staff contacted six staff members of NIDRR-funded projects to ask questions about their experiences with human research participant protection and interactions with the Institutional Review Board (IRB) at their respective institutions. Those interviewed included two individuals from private non-profit organizations, two from large public university-based settings, and two from a private hospital.

### Status of research projects: exempt, expedited, or full review?

One institution presents proposals that are generally exempt, while the other five had some research and some non-research proposals, such as training, dissemination and utilization, and demonstrations. The determination of whether or not a project is exempt is made by the IRB, not the project Principal Investigator. (See Sidebar on *Research and Exempt Research Activities* on p. 13.) One respondent indicated that many of their proposals reflected minimal risk to human participants, and thus go through expedited review by the IRB.

### What IRBs do grantees use?

Half of the grantees interviewed had their own IRB. The IRB of a primary contractor was used by one private non-profit, for a fee. This organization is working on setting up its own IRB in the future, as more research activities are planned. The hospital grantee uses the IRB of a health alliance of several hospitals and other health agencies, in their large metropolitan city. One of the universities has a separate IRB for medical research.

### Characteristics of grantees' IRBs

The size of the IRBs ranged from 5 to 14 members. The university boards included faculty from a variety of disciplines. Outside members included faculty from local educational institutions, medical personnel, lawyers, and representatives of consumer and community groups. The IRBs often invite experts to participate when a special need arises.

The private non-profit groups did not have a Multiple Project Assurance (MPA), but both are applying for the new Federalwide Assurance (FWA). Both universities currently have the MPA and are applying for the FWA. The hospital was not eligible for a MPA, but did apply for and recently received a FWA. This should make things easier for researchers as other agencies will also accept the FWA.

### Process of IRB approval

Grantees indicated that at least preliminary, if not full, approval of the IRB is usually sought before a proposal is submitted. It is time-consuming to have the IRB review a project that ultimately is not funded, so a full review may be delayed until funding notification. The paperwork is prepared but not submitted to the IRB for action until funding is awarded.



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Information is submitted to the IRB, describing the project and its potential risks and benefits, how subjects will be recruited, the informed consent process, privacy procedures and recordkeeping. At the IRB meeting, researchers may be asked to further explain or to make changes for the purpose of improving the protection of human participants in their research.

In general, the process takes around 30-45 days. Most IRB's meet once a month. At times, an additional meeting will be called, but usually the paperwork is prepared and turned in around two weeks ahead of time, and then dealt with at the meeting. Responses are usually given soon after the meeting.

## Research and Exempt Research Activities

The ED Regulations for the Protection of Human Subjects, Title 34, Code of Federal Regulations, Part 97, give definitions for research and human subjects, and identify categories of exempt research activities that are not covered by the regulations.

**Research** is defined as *"a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge."* If an activity follows a deliberate plan whose purpose is to develop or contribute to generalizable knowledge, it is research. Activities which meet this definition constitute research whether or not they are conducted or supported under a program which is considered research for other purposes. For example, some demonstration and service programs may include research activities.

**Human subject** is defined in the regulations as *"a living individual about whom an investigator (whether professional or student) conducting research obtains (1) data through intervention or interaction with the individual, or (2) identifiable private information."*

**Exemptions.** Research activities in which the **only** involvement of human subjects will be in one or more of the following six categories of *exemptions* are not covered by the regulations.

(1) Research conducted in established or commonly accepted educational settings, involving normal educational practices, such as:
   (a) research on regular and special education instructional strategies, or
   (b) research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.

(2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless:
   (a) Information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and
   (b) Any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

*If the subjects are children, exemption 2 applies only to research involving educational tests and observations of public behavior when the investigator(s) do not participate in the activities being observed. Exemption 2 does not apply if children are surveyed or interviewed or if the research involves observation of public behavior and the investigator(s) participate in the activities being observed.* [Children are defined as persons who have not attained the legal age for consent to treatments or procedures involved in the research, under the applicable law or jurisdiction in which the research will be conducted.]

(3) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior that is not exempt under paragraph (b)(2) of this section, if:
   (a) The human subjects are elected or appointed public officials or candidates for public office; or
   (b) Federal statute(s) require(s) without exception that the confidentiality of the personally identifiable information will be maintained throughout the research and thereafter.

(4) Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.

(5) Research and demonstration projects which are conducted by or subject to the approval of department or agency heads, and which are designed to study, evaluate, or otherwise examine:
   (a) Public benefit or service programs;
   (b) Procedures for obtaining benefits or services under those programs;
   (c) Possible changes in or alternatives to those programs or procedures; or
   (d) Possible changes in methods or levels of payment for benefits or services under those programs.

(6) Taste and food quality evaluation and consumer acceptance studies,
   (a) If wholesome foods without additives are consumed or
   (b) If a food is consumed that contains a food ingredient at or below the level and for a use found to be safe, or agricultural chemical or environmental contaminant at or below the level found to be safe, by the Food and Drug Administration or approved by Environmental Protection Agency or the Food Safety and Inspection Service of the U.S. Department of Agriculture.

From *Definitions for Form ED 424, Application for Federal Education Assistance*. Available: **http://www.ed.gov/offices/OCFO/grants/appforms/ed424.pdf**



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When suggested changes are re-submitted, approval is quick. If many changes are suggested, it may take longer.

Expedited reviews, in cases where the research is judged to have a low risk of harm, do not require attention from the full board. These reviews most often take just a couple of weeks.

### Grantee interactions with IRBs

All but one of the grantees interviewed reported they had to make some changes on one or more research proposals submitted to their IRB. In most cases, changes were small, refining some wording here and there. Changes to the informed consent forms were required most often. Other changes required by grantee IRBs focused on collaborative projects, to clarify the roles of each partner in the study. A number of years ago, one university-based grantee shared information on qualitative research techniques with members of the IRB, to help clarify the proposed study.

None of the grantees had ever had a proposed project turned down by their IRB. All six interviewees reported they feel the process is working well with the IRB and their institution. Changes requested were seen as clear and helpful, and once made, were expedited so that implementation was not delayed.

Grantees were asked how often they communicate with the IRB. Most mentioned whenever there was a need for a change in a protocol or procedure. The IRB would expedite review of the proposed changes and get back to the grantees promptly. Researchers must keep the IRB informed as lack of communication could jeopardize research at the institution as a whole. An annual review is required of projects that are ongoing for more than one year. Grantees had not been in a situation of needing to report adverse events to their IRB.

### Special considerations for study participants with disabilities

The interviewees were asked what special considerations the IRB looks for regarding informed consent and other issues for study participants with disabilities. Several interesting responses were generated. One grantee noted that some researchers do not know how to talk to and include people with cognitive problems, and often this group of consumers is excluded.

One respondent described a two-fold problem. Some people are unable to articulate their consent, so there must be a process for surrogate/guardian decision-making. Researchers should still attend to the non-verbal behaviors of people to determine if they do or do not want to participate. The second issue is ensuring that people with disabilities are not excluded. There should be a balance of protection and respect for autonomy, depending on the risks involved.

Another grantee stressed using clear language to avoid "overpromising" about potential results. Statements are needed to ensure understanding that a person can quit at any time without repercussions. Another concern is that "competence" changes for some people with cognitive disabilities. Family should be consulted, but the person should also be involved and for each step in the process, his or her wishes should be acknowledged.

### Collaborative projects

All the grantees that have worked on collaborative projects with different funding agencies and cooperating institutions with different IRBs commented on the additional layer of complexity that is added. It is most difficult when each agency's IRB must approve the total project. It is important to provide information to all collaborators. Grantees advised that the project should be structured so that each IRB can review their agency's part and not have to review the efforts of another agency. When several IRBs have to review, often many small changes are needed to make everyone happy. One grantee described a large consortium project that involved 21 IRBs!

### Training on human subjects protection

Training on human research participant protection issues is required of grantees of NIH and will likely be required by other funding agencies in the future. Four grantees interviewed reported they had participated in the following training: HHS Web-based training; online papers, IRB chair guidebook; training to be an IRB member; and NIH online course. Two grantees had not received specific training, although one is working on developing an internal training packet for their hospital.

### Establishing and maintaining successful relationships with IRBs

Grantees were asked to identify the most important elements of a successful presentation of a research proposal to an IRB. Responses included:

- Be well-organized, have all forms complete, and be conversant with all the issues.
- Be prepared and knowledgeable about the project, with research protocol, consent forms, explanation of recruitment in place.
- Be straightforward and clear in describing variables and procedures. Know your participant population.
- Know the requirements; be thorough.
- Be complete with regard to details… who, why, how? For example, have procedures in place to protect locked materials, etc.

Grantees were also asked to offer their "tips" for a successful IRB review:

- When appropriate, frame research in terms of minimal risk to facilitate an expedited review. Look at the categories for exemption and let the IRB know if your study qualifies. Remember that no research can be risk-free, however.
- Be realistic in describing potential benefits.
- Be collegial and do not treat the IRB as an obstacle.
- If you are doing something a little "different," bring some citations and examples, to help explain what you propose to do.
- Be careful to use plain, understandable language on consent forms (no jargon).
- If you are new to the process, sit in on an IRB meeting to get an idea of what you will need to do, and the kinds of things the IRB members are looking for.
- Find a mentor to review your paperwork before submitting it to the IRB.

### Improving the IRB process

Grantees were asked to give suggestions they felt would improve the process of presenting research proposals to an IRB.

Most grantees responded that things were working well at their institutions, but some suggestions were offered to improve the general process.

- One grantee noted that he had been asked to sign a consent form when interviewed as an expert in the field. This is not needed as it is not human participant protection and serves to detract from the process.
- It would be a help to stabilize and clarify requirements from the Federal government to ensure that researchers are clear on IRB expectations.
- Cutting down on paperwork would help streamline the process. Would it be possible to make forms available online?
- Private non-profit organizations have less experience than university-based researchers. More training is needed for these researchers.
- Accreditation is positive as it implies greater scrutiny. However, don't lose sight of *why* IRBs exist. Getting hung up in another level of paperwork could destroy the credibility of the process.
- Specify the 'standards of excellence' in the core IRB requirements.
- Some projects like Dissemination and Utilization projects may use a different research method, such as focus groups. Yet, the expectations are the same as for other research projects although it may not be a good fit. It would help if expectations were clearer.
- How about a question on a proposal application that says "Do you have IRB materials ready? Submit a copy with proposal." In other words, clarify that it is OK to wait until funding is secured before presenting to the IRB.

### Summary

Overall, the grantees reported that interaction with their IRB was positive. All agreed that there is a lot of additional paperwork involved, but it is needed as long as it focuses on protecting the rights of study participants. Researchers take the issues of confidentiality, informed consent, protection, selection, and feedback very seriously.



# The Association for Accreditation of Human Research Participant Protection Programs (AAHRPP)

The Association for Accreditation of Human Research Participant Protection Programs (AAHRPP) was incorporated as a not-for-profit organization in April, 2001, to offer accreditation to institutions engaged in research involving human participants. AAHRPP is the first organization of its kind in the field of human participant protection.

AAHRPP was created by seven member organizations representing the leadership of universities, medical schools and teaching hospitals; biomedical, behavioral, and social scientists; IRB experts and bioethicists; and patient and disease advocacy organizations:

- Association of American Medical Colleges
- Association of American Universities
- Consortium of Social Science Associations
- Federation of American Societies for Experimental Biology
- National Association of State Universities and Land Grant Colleges
- National Health Council
- Public Responsibility in Medicine and Research

"Responding to increased public and political scrutiny, AAHRPP seeks not only to ensure compliance, but to raise the bar in human research protection by helping institutions reach performance standards that surpass the threshold of state and federal requirements.

By establishing a 'gold seal' signifying adherence to a rigorous set of human protection standards, accreditation by AAHRPP will help ensure consistency and uniformity among all institutions conducting biomedical, behavioral and social sciences.

AAHRPP works to protect the rights and welfare of research participants by fostering and advancing the ethical and professional conduct of persons and organizations that engage in research with human participants. AAHRPP achieves its mission by using an accreditation process based on self-assessment, peer review, and education" (from About us, Available: **http://www.aahrpp.org/about.htm**).

Dr. Marjorie Speers, Executive Director, talked with the NCDDR about the organization and some of its goals (Marjorie Speers, personal communication, December 12, 2001). Dr. Speers was on assignment from the Centers for Disease Control for two years to serve as project director with the National Bioethics Advisory Committee (NBAC). The NBAC was established to examine and make recommendations on bioethical issues related to research on human biology and behavior. She was Acting Executive Director during the NBAC's final months, and became Executive Director of AAHRPP in October, 2001.

**• Who will be accredited by AAHRPP?**

The goal of AAHRPP is to serve all researchers, from large university research centers to small and independent programs. Universities and colleges, hospitals, for-profit and non-profit organizations, government agencies, independent IRBs--all types of research settings are envisioned as benefiting from this effort to scrutinize the quality of programs to protect research participants.

AAHRPP does not believe there is one "right" model, but wants the standards to be broad enough and flexible enough to be useful in a range of settings.

Several of the founding organizations of AAHRPP represent colleges and universities, and many institutions of higher education are expected to participate in the accreditation program.

**NOTE:** Who is eligible for accreditation? is now available on the AAHRP Website: **http://www.aahrpp.org/eligibility.htm**

**• What is the accreditation process, and how much does it cost?**

Organizations that apply for accreditation will be asked to conduct a self-assessment to provide a program description to the AAHRPP staff. Then an on-site assessment will be conducted. Both the self-assessment and on-site accreditation visit will use the *Accreditation Standards* and *Procedures* developed by AAHRPP. If the standards are met, the organization will be accredited for a period of three years. Pilot testing began in December, with the National Institutes of Health.

Accreditation will be offered once the pilot test and revision of the Interim Standards have been completed. The fees have not yet been set but will be determined following the pilot testing experience, which includes accreditation visits to five varied sites. Fees will be on a sliding scale based on the size of the organization and its research program, the clinical or non-clinical nature of the research program, as well as the number of IRBs affiliated with the organization.

**NOTE:** The *Accreditation Procedures* are now available on the AAHRP Website:

**http://www.aahrpp.org/procedures_print.htm** *and*

**http://www.aahrpp.org/images/procedures.PDF**

**NOTE:** *A Fee structure for 2002* is now available on the AAHRP Website:

**http://www.aahrpp.org/fees.htm**

**• When will the Accreditation Standards and Procedures be released?**

The *Interim Accreditation Standards* and *Procedures* were released in September, 2001. AAHRPP accepted comments through December 3, 2001. A substantial number of comments were received, and are still being reviewed in preparation for analysis. Many of the comments have been supportive. The analysis of the comments will be used to make changes and revisions to the Standards.

The development of the *Interim Standards* was initiated by the group Public Responsibility in Medicine and Research (PRIM&R). Findings from *Preserving Public Trust*, a report from the Institute of Medicine on accreditation of human research protection programs, are also incorporated into the *Interim Standards*. The pilot test is using the *Interim Standards* for both the self-assessment and accreditation visits.

**NOTE:** The *Final Standards* were released on February 12, 2002, and are available on the AAHRP Website:

**http://www.aahrpp.org/standards.htm** *and*

**http://www.aahrpp.org/images/standards.PDF**

# Federal Government Backs New Award Program to Promote Best Practices in Human Research Protection

*November 14, 2001 — Bethesda, MD*

The Office of Human Research Protections (OHRP), US Department of Health and Human Services, has awarded a contract to the Health Improvement Institute (HII) to create a national awards program recognizing excellence in protection of human research subjects. The awards will become part of a public-private partnership that will encourage ongoing improvement in the nation's system for protection of human research subjects by giving visibility to best practices and by rewarding institutions, investigators, sponsors and review boards for their commitments to responsible conduct of human studies.

According to Greg Koski, Director of OHRP, "These *Awards for Excellence in Human Research Protection* will encourage institutions, investigators and sponsors to continually improve their processes. For too long we have focused on regulatory compliance as an end in itself — what we need to emphasize is prevention of harm. These awards will heighten awareness of these issues within the research community and among the general public, adding credibility to the research process and raising public confidence in research results. We believe that the research community, industry, and the American public share these goals and these awards will recognize the best among those who achieve them."

The Health Improvement Institute **http://www.hii.org** of Bethesda, Maryland — a non-profit, tax exempt organization that promotes improving the quality and productivity of America's health care — created this new series of awards. "There is excellent and ethical research being done throughout the United States and these new awards celebrate the individuals and organizations who do it best," said Dr. Peter Goldschmidt, President of HII.

For more information about the awards competition, please contact **Kristin Hollingsworth** at **(301) 652-1818** or by email: **kjh@mcman.com**

Source: **http://www.hii.org/151.htm**
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**NOTE:** The *Principles for Accreditation of Human Research Protection Programs* are now available on the AAHRP Website:

**http://www.aahrpp.org/accreditation_principles.htm** *and*

**http://www.aahrpp.org/images/principles.PDF**

**• Does the AAHRPP plan to offer training or other activities?**

At this time, AAHRPP has no plans to provide specific training to its accredited clients. However, AAHRPP will gather information about a wide range of programs and will make it available to its clients. New ideas and ways to deal with problems will also be shared.

As a non-profit agency, AAHRPP is not a political organization. Its founding members came together to provide a response from within the research community to the need to improve the process and oversight of human research participant protection. The pursuit of accreditation reflects a serious commitment to protecting participants by setting the bar higher than the standards required by law. AAHRPP will affect policy by blazing the way to developing higher quality programs at accredited research institutions to protect research participants.

Dr. Speers or her designate representing the AAAHRPP may be invited to serve on one or more of the various committees working to improve human research participant protection. There are a number of federal agencies and organizations examining this issue. At this time, there is no one 'leader' or coordinating body. Recommendation 2.1 of the report on *Ethics and Policy Issues in Research Involving Human Participants*, the 2001 report of the NBAC, was "to create a single independent federal office.... to lead and coordinate the oversight system, and be responsible for policy development, regulatory reform, research review and monitoring, research ethics education, and enforcement."

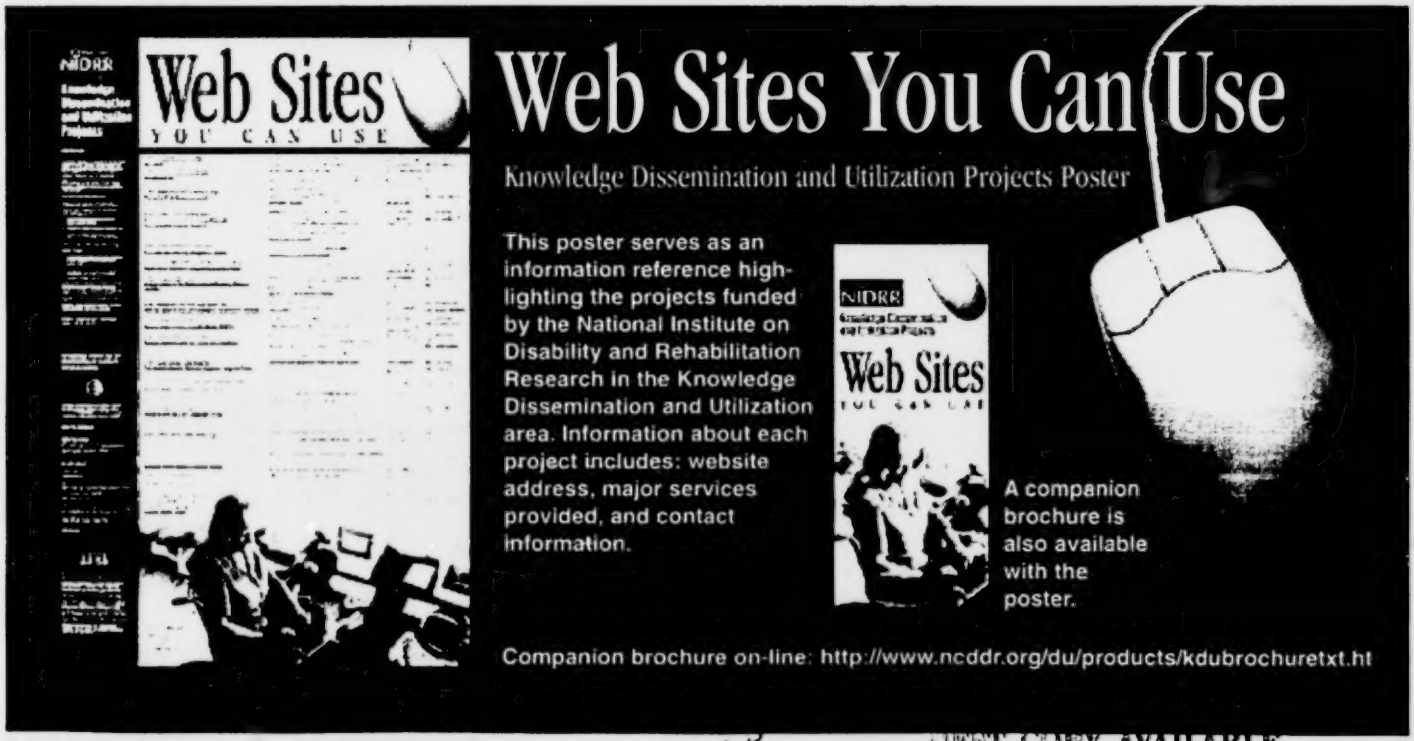
**• Would the Director of AAHRPP like to share anything else with the community of NIDRR researchers?**

Dr. Speers said she believes it is important for researchers to know about the new accreditation process, and to inquire if their institutions will seek accreditation. AAHRPP accreditation is available to all organizations engaged in research, regardless of whether or not they are based in a university. Researchers can benefit because institutions that obtain accreditation are committed to providing a high level of protection for research participants. Such institutions support their researchers and convey to the public that they are dedicated to protecting their local citizens who enroll in research studies.

The *Accreditation Standards* and *Accreditation Procedures* are designed to be comprehensive and flexible, and to be applied to different types of research and settings. Dr. Speers emphasized that this organization is the result of an initiative from within the community of researchers, and will be responsive to what researchers need. Those institutions that are accredited will demonstrate that their research programs include exemplary provisions for protecting the participants in that research.

The AAHRPP is located in Washington, DC. The Web site is **http://www.aahrpp.org/**

**Dr. Marjorie Speers,**
**Executive Director**
**AAHRPP**
**915 15th Street, N.W., 9th Floor**
**Washington, DC 20005**
**(202) 783-1112**
**(202) 783-1113 (fax)**


NIDRR
Web Sites
YOU CAN USE
Web Sites You Can Use
Knowledge Dissemination and Utilization Projects Poster
This poster serves as an information reference highlighting the projects funded by the National Institute on Disability and Rehabilitation Research in the Knowledge Dissemination and Utilization area. Information about each project includes: website address, major services provided, and contact information.
A companion brochure is also available with the poster.
Companion brochure on-line: http://www.ncddr.org/du/products/kdubrochuretxt.ht



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# Resources On Human Research Participants Protection

## Articles and reports

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## Government and organization web sites

Association for the Accreditation of Human Research Protection Programs (AAHRPP)
**http://www.aahrpp.org/**

Centers for Disease Control and Prevention (CDC)
Human Subjects Research
**http://www.cdc.gov/od/ads/hsr2.htm**

Consortium of Social Science Associations (COSSA)
**http://www.cossa.org/**
Compilation of Stories on Human Participants Protection
**http://www.cossa.org/humansubjects.htm**

Food and Drug Administration (FDA)
Good Clinical Practice in FDA-Regulated Clinical Trials
**http://www.fda.gov/oc/gcp/default.htm**
Institutional Review Boards & Protection of Human Subjects in Clinical Trials
**http://www.fda.gov/cder/about/smallbiz/humans.htm**

Institute of Medicine (IOM)
Committee on Assessing the System for Protecting Human Research Participants
**http://www.iom.edu/IOM/IOMHome.nsf/Pages/human+research+protections**

National Institutes of Health (NIH)
Office of Human Subjects Research
**http://ohsr.od.nih.gov/**
Guidelines for the Conduct of Research Involving Human Subjects at The National Institutes of Health
**http://ohsr.od.nih.gov/guidelines.php3**
Bioethics Resources on the Web
**http://www.nih.gov/sigs/bioethics/**
Human Participants Protection Education for Research Teams
**http://cme.nci.nih.gov/login.htm**

National Council of University Research Administrators (NCURA)
The Online Companion to the Fundamentals of Sponsored Project Administration: Compliance
**http://www.ncura.edu/members/fundamentals/FundamentalsSection.asp?PageID=4**

Public Responsibility in Medicine and Research (PRIM&R)
Publications: Conflict of Interest
**http://www.primr.org/conflictpub.html**
Publications: Human Subjects Protection
**http://www.primr.org/humanpub.html**

U.S. Department of Education (ED) Protection of Human Subjects in Research
**http://www.ed.gov/offices/OCFO/humansub.html**
Excerpts from 34 CFR Part 350 and 34 CFR Part 356, Disability and Rehabilitation Research
**http://www.ed.gov/offices/OCFO/humansub/34cfr350.html**
Protection of Human Subjects Provision and Clause
**http://www.ed.gov/offices/OCFO/contracts/clibrary/humansub.html**

U.S. Department of Energy (DOE), Protecting Human Subjects
**http://www.science.doe.gov/ober/humsubj/hsindex.html**
Advisory Committee on Human Radiation Experiments (ACHRE)
**http://tis-nt.eh.doe.gov/ohre/roadmap/achre/index.html**
DOE Openness: Human radiation experiments.
**http://www.tis.eh.doe.gov/ohre/index.html**

U.S. Department of Health and Human Services (HHS) Office for Human Research Protections
**http://ohrp.osophs.dhhs.gov/**
The Belmont Report
**http://ohrp.osophs.dhhs.gov/humansubjects/guidance/belmont.htm**
National Human Research Protections Advisory Committee (NHRPAC)
**http://ohrp.osophs.dhhs.gov/nhrpac/nhrpac.htm**

U.S. Department of Veterans Affairs (VA)
Human Research Protection Accreditation Program developed by National Committee for Quality Assurance (NCQA)
**http://www.ncqa.org/Programs/QSG/VAHRPAP/vahrpap.htm**

U.S. Food and Drug Administration (FDA) Information Sheets
**http://www.fda.gov/oc/ohrt/irbs/**
21 CFR Part 50 - Protection of Human Subjects
**http://www.fda.gov/oc/ohrt/irbs/appendixb.html**

United States Holocaust Memorial Museum: The Doctors Trial
**http://www.ushmm.org/research/doctors/**
The Nuremberg Code
**http://www.ushmm.org/research/doctors/Nuremberg_Code.htm**

## Selected university-based online tutorials

California State University, Long Beach
**http://www.ur.csulb.edu/rcrhs.htm**

Collaborative IRB Training Initiative (CITI)
**http://www.miami.edu/UMH/CDA/UMH_Main/1,1770,6460-3,00.html**

Harvard University
**http://vpf-web.harvard.edu/osr/support/human_subject/index.htm**

Indiana University
**http://www.indiana.edu/~rcr/srv01.phtml**

Johns Hopkins Medicine
**https://secure.lwservers.net/jhmrct/**

Kansas University Medical Center
**http://www2.kumc.edu/instruction/research/humansubjects/**

Kansas Wesleyan University
**http://www.kwu.edu/irb/Modules.htm**

Penn State Hershey Medical Center/Penn State College of Medicine
**http://www.hmc.psu.edu/hmc-irb/ppt/protsub2/v3dcmnt.htm**

Stanford University
**http://www.stanford.edu/dept/DoR/hs/**

University of Arizona
**http://vpr2.admin.arizona.edu/rie/HumanSubjectsTraining.htm**

University of California at Los Angeles
**http://training.arc.ucla.edu/**

University of California, San Diego
**http://rcr.ucsd.edu/index.html**

University of Illinois at Chicago
**http://www.uic.edu/depts/ovcr/oprs/Education/index.html**

University of Michigan
**http://www.umich.edu/~drda/index.html**

University of Minnesota
**http://www.research.umn.edu/subjects/**

University of Wisconsin — Madison
**http://www.rsp.wisc.edu/humansubs/training/new/start.htm**

# What do Professional and Consumer Organizations Have to Say?

A number of organizations have issued policy statements related to the topic of protecting participants in research. Some examples from consumer-based groups are given and links to professional group policies are provided.

### Alliance for Human Research Protection (AHRP) Mission Statement:

We are a national network of lay people and professionals whose mission is to ensure that research involving human beings is conducted in accordance with ethical and professional standards as enshrined in the Hippocratic Oath, "first, do no harm;" The Nuremberg Code; and the Declaration of Helsinki. AHRP's mission is to ensure that the human rights, dignity, and welfare of human research subjects are protected. We are committed to advance responsible conduct in research and ethical treatment of human research subjects; and to ensure that the inalienable right of every human being to voluntary, informed, comprehending consent to research is respected. Our public awareness efforts are geared to ensure that disadvantaged vulnerable populations, such as, children, mentally and physically disabled, and the elderly, are not exploited in painful experiments involving high risk of harm, or non-approved experimental interventions, because of their inability to defend themselves.

The Alliance for Human Research Protection will use public ensure to further our human rights and social justice mission.

**Contact:**
**Vera Hassner Sharav**
**(212) 595-8974**
**veracare@rcn.com**
**http://www.researchprotection.org/**

### National Alliance for the Mentally Ill (NAMI)

Summary of NAMI's Policy on Research: NAMI members strongly support severe mental illness research, including research involving human subjects, as this is the basis for all future advances in treatment. However, research involving human subjects must be in accord with the highest scientific, medical, and ethical standards and must protect and honor the individuals and families who make this contribution to scientific progress. Specifically, NAMI demands that: 1) research subjects give truly informed consent and that they and their families fully understand the protocols and risks and benefits of the research; 2) researchers perform independent and ongoing evaluations of research-subject capacity to consent; 3) IRBs include consumers and family members: 4) consumers may withdraw from a study at any time without penalty; 5) at the end of the study, or if a consumer terminates participation

## Links to Statements of Professional Groups on Human Subject Protection

**American Educational Research Association (AERA)**
Ethical Standards of AERA
**http://www.aera.net/about/policy/ethics.htm**

**American Physiological Society (APS)**
Human Subjects Protection Pledge
**http://www.the-aps.org/pub_affairs/archives/pa_human_subjects.htm**

**American Psychological Association (APA)**
Ethical Principles of Psychologists and Code of Conduct
**http://www.apa.org/ethics/code.html**

**Association of American Universities (AAU)**
**http://www.aau.edu/research/HumSubPressRelease06.28.00.pdf**
See **http://www.aau.edu/research/integri.html** for links to more than 20 reports, statements, and news releases related to Human Subjects Research.

**Association of Clinical Research Professionals (ACRP)**
ACRP Code of Ethics:
**http://www.acrpnet.org/ethics/index.html**

**Emergency Nurses Association (ENA)**
Position Statement: Protection of Human Subjects' Rights
**http://www.ena.org/services/posistate/data/prohum.htm**



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prematurely, ongoing effective treatment and aftercare are ensured as is feedback on the study results.

Note: The complete text of NAMI's policy on research is available on the NAMI Web site: **http://www.nami.org/update/platform/research.htm**

Source (used with permission): **http://www.nami.org/research/policy.html**

see also **http://www.nami.org/update/unitedprotect.html**

### WheelchairNet

WheelchairNet is a virtual community of people who care about wheelchairs. A statement on *Human Subjects: What research participants should know!* provides an overview of the federal regulations and their impact, from the perspective of a research study participant. Links are provided to the Office for Human Research Protection (previously Office for Protection from Research Risks) and to the web site of the IRB of the University of Pittsburgh, the sponsor of the RERC on Wheeled Mobility and WheelchairNet.

> "The bottom line for research study participants is that the IRB which is regulating and approving the research study you are involved in has your best interest at heart. It is required that a consent form offer you the phone number and contact information so you can easily and confidentially reach the specific IRB office. Don't be afraid to ask questions or to questions unresolved issues. People who act as research study participants deserve to be treated fairly and carefully and with respect for the contribution that they are making to science."

Written by Mary Ellen Buning, MS, OTR/L, ATP with materials taken from the *Manual of the Institutional Review Board* of the University of Pittsburgh, Pittsburgh, PA, 15260.

Source (used with permission): **http://www.wheelchairnet.org/WCN_WCU/Research/Researchinfo.html**

## Who's in the News

Members of the NCDDR staff are on the lookout for popular and disability media pieces that present research funded by NIDRR. In this issue, we share news items from the ***Pittsburgh Post-Gazette***, the ***New York Times***, and the ***Chicago Sun-Times***. Please let the NCDDR know when an item representing your NIDRR-funded project appears in the media.

Call us, **1-800-266-1832**, or send email to **pcastane@sedl.org** and the item will be reviewed for *Who's in the News*. You may also use an online form: **http://www.ncddr.org/forms/submitnews.html**

*Widening the Web's reach*
*Spurred by new federal law, companies are moving to bring the Internet to visually and hearing impaired*

By **Eve Modzelewski, *Pittsburgh Post-Gazette*** Staff Writer

The article in the ***Pittsburgh Post-Gazette*** on August 12, 2001 presents information about Web/technology accessibility requirements of Section 508. Amy Goldman, program director for Pennsylvania's Initiative for Assistive Technology (PIAT) at Temple University, was contacted by the journalist and interviewed. Ms. Goldman said Section 508 and Pennsylvania's state guidelines would have far-reaching effects, beyond what's provided for in the ADA.

"You had the ADA 10 years ago... and there have still been electronic information technology products that have been inaccessible," Goldman said. "We're in an environment where there's increasing dependence on those technologies by the whole of society."

Goldman has noticed that businesses, especially those looking for federal contracts, clearly are concerned about compliance with Section 508. Still, she said there needs to be more awareness among Web designers working in areas such as education.

"I'm not sure that there's a great deal of awareness on the part of persons with disabilities that there are these protections," Goldman said. To spread the word about accessibility, PIAT held a November conference in Harrisburg centered on Section 508 and its relevance to government, industry and the disabled community. For more information, contact **Amy Goldman** at **(215) 204-3862**.

The Rehabilitation Engineering Research Center: Improved Technology Access for Land Mine Survivors located at the Center for International Rehabilitation (CIR) in Chicago had articles in national and local newspapers. The August 30, 2001 issue of the ***New York Times*** presented an article by Bonnie Rothman Morris, "Online Course Lets the Isolated Bring Their Medical Skills Up to Date." Ms. Morris indicated that a public relations firm gave her information about the project, and she followed up with the Center for International Rehabilitation to learn more. She thought it would make an interesting story and her editors at the *New York Times* agreed.

The article describes a pilot program, an online training course on prosthetic techniques made available to 23 prosthetists in El Salvador, Nicaragua and Guatemala. The program was developed by the CIR, a three-year-old organization in Chicago that works to help victims of land mines. When the relief workers leave, the health problems remain for amputees, especially children, who need to be monitored, fitted and refitted with new prosthetics.

"People with disabilities need a lifetime commitment," said Dr. William Kennedy Smith, director of the Center for International Rehabilitation and president of Physicians Against Land Mines.

The lessons for the prosthetics course were developed at the Northwestern University Prosthetic Orthotic Center. Web CT, a company based in Lynnfield, Mass., that produces educational software for universities, donated software and technical support, including translation of the materials from English into Spanish. The course consists of an online field manual that can be updated as technology,



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information and students' questions change. Students commit to one hour a day of online study, at no cost, and have access to mentors through chat rooms, where they talk to each other in real time. There are also bulletin boards where questions and responses can be posted.

The students are provided with a CD-ROM that has supplemental video and audio materials that would take too long to download given the slow-speed connections that are the norm in El Salvador and other countries. For the pilot project, an instructor is also traveling throughout Central America to meet with each student for a hands-on clinical workshop, and for the final evaluation before awarding the certificate.

On October 3, 2001, a letter to the editor from Dr. Smith was printed in the ***Chicago Sun-Times***. His letter described the extensive use of land mines in Afghanistan over many years. PALM supports United States military action, yet urged the U.S. not to deploy new antipersonnel mines in Afghanistan and to exercise care regarding humanitarian food drops in mine-affected areas.

In a follow-up, *Chicago Sun-Times* staff reporter **Art Golab** interviewed Dr. Smith for an article published on October 14, 2001. For more information on these articles, contact Deanna Kepka, Communications and Development Manager at the Center for International Rehabilitation: **dkepka@cirnetwork.org**

## NIDRR Grantee and Staff Recognition

The NCDDR continues to share the recognition given to NIDRR-funded researchers and their staff. All grantees are encouraged to send this information to the NCDDR for future issues.

Send email to **pcastane@sedl.org**, call **1-800-266-1832**, or use the online form available on the NCDDR Web site: **http://www.ncddr.org/forms/submitrecog.html**

**Thomas Bird, MD**, received the *George W. Jacoby Award* from the American Neurological Association and presented the Jacoby Lecture Oct. 1, 2001 at the Association's 126th annual meeting. Dr. Bird is a professor of neurology and medicine, chief of the Division of Neurogenetics in the Department of Neurology and serves on the research faculty in geriatrics at the Veterans Affairs Puget Sound Health Care System. He also collaborates with UC Davis School of Medicine clinical professors on the research project, "Risks and Benefits of Genetic Testing in Persons with Hereditary Neuromuscular Disease," funded by NIDRR through the **RRTC in Neuromuscular Diseases** (RRTC/NMD), in the Department of Physical Medicine and Rehabilitation.

The *Jacoby Award* is presented every third year to an American Neurological Association member who has done especially meritorious experimental work. Dr. Bird is honored for his studies of hereditary neurological disorders including ataxias, Charcot-Marie-Tooth neuropathy, Huntington's disease and spastic paraplegia. At the Jacoby Lecture, he discussed ethical issues in neurogenetics that are emerging from genomic neurology and that will confront most neurologists in the near future.

For further information, contact **Dr. Kathryn Devereaux** of the RRTC/NMD by email: **kdevereaux@ucdavis.edu**

Dr. Bird can be reached at **206-764-2308** or tomnroz@u.washington.edu

News of Dr. Bird's research may be found at the following Web sites:
**http://www.rehabinfo.net/RRTC/Newsletters/ProgramOverview99/GeneticTesting.html**

**http://www.geneclinics.org/profiles/cmt/**

**http://depts.washington.edu/neurogen/**

The **Southeast Disability and Business Technical Assistance Center** (Southeast DBTAC) is the proud recipient of the *2001 Citation Group Award* presented on April 26, 2001 by the South Carolina International Association of Personnel in Employment Security (IAPES) at its annual convention. The SE DBTAC was nominated for its provision of training, technical assistance and information resources on the Americans with Disabilities Act (ADA) for the South Carolina Employment Security Commission. "They have assisted us in every way possible to provide a leadership role to employers, people with disabilities, governmental entities, and other organizations. As a result, we have developed a successful statewide infrastructure that creates pubic awareness of the ADA, disseminates accurate information, and provides quality technical assistance and training." The SE DBTAC is deeply appreciative of this recognition, and the beautiful plaque hangs proudly on the main entrance wall.

For more information, contact **Pamela Williamson**, Assistant Director, **pam.willamson@catea.org** or **Shelley Kaplan**, Project Director, **sedbtac@ catea.org**

**Mitchell Rosenthal, Ph.D.**, was chosen as the first recipient of the internationally recognized *Robert L. Moody Prize for Distinguished Initiatives in Brain Injury Research and Rehabilitation*. The prize was presented to Dr. Rosenthal at the second annual Galveston Brain Injury Conference, November 2-4, 2001. The Conference was sponsored by The University of Texas Medical Branch and The Transitional Learning Center of Galveston.

Dr. Rosenthal was selected for this award based on significant contributions



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in brain injury research over 26 years, including work in the NIDRR-funded **Traumatic Brain Injury Model Systems** program for the last ten years. He has served as Project Director of the **TBI National Data Center** since 1993, which is housed in the Kessler Medical Rehabilitation Research and Education Corporation. Dr. Rosenthal has published over 100 peer-reviewed articles, abstracts, and book chapters, serves as senior editor of the leading scientific journal in the field, *Journal of Head Trauma Rehabilitation*, and is a founding member of the Brain Injury Association.

Upon receiving news of his distinguished honor, Dr. Rosenthal stated, "This recognition provides strong encouragement to continue my efforts to conduct and promote research which leads to a better understanding of how individuals with brain injury and their families are impacted by a severe brain injury and what rehabilitation interventions are most effective in maximizing recovery, independence in the community, and the highest possible quality of life."

The *Moody Prize* is named after Robert L. Moody, whose sustained personal dedication after his son sustained a brain injury has created a legacy of clinical accomplishment in rehabilitation education, service and research. The prize builds awareness of the significant public health implications of brain injury and aims to increase national and international awareness of the need to expand research and improve treatment for persons who have experienced brain injury. The *Robert L. Moody Prize* is administered by a board of governors and awards are considered by a panel of experts.
For more information, contact **Dr. Rosenthal** by email: **mrosenthal@kmrrec.org**

**William Kennedy Smith, MD**, was invited to participate as one of four panelists at a Chicago-based *National Town Hall Meeting* sponsored by the United Nations on October 11, 2001. **Dr. Smith** is the PI for the **RERC: Improved Technology Access for Land Mine Survivors**. He is director of the Center for International Rehabilitation and President of Physicians Against Land Mines (PALM).

National Town Hall meetings were held in Atlanta, Boston, Chicago, Denver, Houston, Los Angeles, Minneapolis, Seattle, St. Louis and Tampa, starting at 9:00 AM Pacific Standard Time to 12:00 PM Eastern Standard Time. These events were designed to allow the American people to engage in a direct conversation with the Secretary-General and their local communities about the impact of the terrible attacks of September 11th and the United Nations' role in the global fight against terrorism. UN Secretary General Kofi Annan was the featured speaker (via satellite from New York) and Walter Cronkite was National Moderator.

For more information, contact **Deanna Kepka**, Communications and Development Manager at the Center for International Rehabilitation: **dkepka@cirnetwork.org**

**Nancy Arnold, Ph.D.**, Director of Research for Employment and Economic Development Projects at the **Research and Training Center on Rural Rehabilitation** (RTC: Rural), University of Montana, was selected as a recipient of a *2001 Congressional Black Caucus Veterans' Braintrust Award*, in conjunction with the 2001 Congressional Black Caucus Annual Legislative Conference. The *Veterans' Braintrust Award* was established by General Colin Powell in 1990 to recognize outstanding national commitment to black veterans. The criteria of community service to further validate the role and contributions made on behalf of veterans' interests was added in later years.

Dr. Arnold has been a national leader in opening entrepreneurial opportunities for people with disabilities. She began her research on self-employment as an option for people with disabilities in 1988, has developed model state and national policies to increase such opportunities, and has worked to provide training and technical assistance to vocational rehabilitation professionals so they in turn help consumers maximize their business success.

For more information, contact **Diana Spas**, RTC: Rural Information Specialist by email: **gargoyle@selway.umt.edu** or call her at **(406) 243-5760**.

On July 26, 2001, the late **Dr. Leonard Kasday** was the recipient of the *Lifetime Achievement Award* from The International Coalition of Access Engineers and Specialists (ICAES). Dr. Kasday's work to improve the accessibility of the World Wide Web for all individuals with disabilities is well known throughout the country and the world. His accessibility checker, the "WAVE," is one of a select number of tools promoted by the government to assist Web designers in improving accessibility. In Pennsylvania, Dr. Kasday was instrumental in the development of standards and policies governing the accessibility of all State web sites. He served as Chair for the Evaluation and Repair Tools Interest Group, World Wide Web Consortium's Web Accessibility Initiative (W3C-WAI).

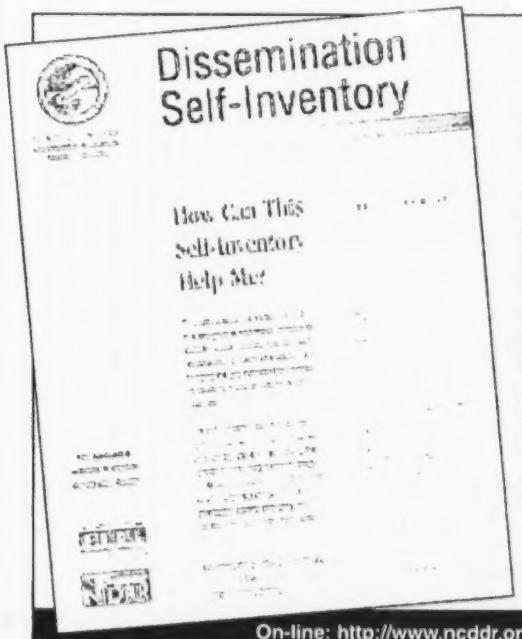
Dr. Kasday was a Universal Design Engineer at the Institute on Disabilities/ UCE at Temple University. He worked with Pennsylvania's Initiative on Assistive Technology (PIAT), funded by NIDRR through the Assistive Technology Act of 1998, and with the RERC on Communication Enhancement (AAC-RERC). He joined the Institute after retiring from a 22-year career at AT&T.

*Doing "IT" Right*, the PIAT Statewide Conference About Access to Electronic and Information Technology (IT) for People with Disabilities, held November 7-8, 2001 in Harrisburg, PA, was dedicated in memory of Dr. Kasday. The Institute on Disabilities/UCE established a graduate assistantship in his memory as well. Contact **Amy Goldman**, Project Director of PIAT, for further information: **piat@astro.ocis.temple.edu**

ICAES is a non-profit membership organization with a mission to foster international cooperation and support for the design of products that are as accessible and usable by persons with disabilities, as economically possible, and technically feasible. Several representatives from NIDRR grantees serve on the ICAES Board of Directors. The purpose of the International Access Engineering Awards Program is to recognize significant innovative technical contributions to the access engineering profession.
For more information, visit **http://www.icaes.org/**

**Dr. Paul Wehman**, Principal Investigator of the **RRTC on Workplace Supports**, was the recipient of the *Distinguished Service Award* on September 6, 2001, at the 2001 Convocation at Virginia Commonwealth University (VCU). This award honors his twenty-five years of service to people with disabilities, including his revolutionary work in the area of supported employment for those with severe disabilities. A ceremony honoring all faculty members, the Convocation has been an annual event at VCU since 1982. Each year four professors receive Distinguished Faculty Awards in the areas of teaching, research, service, and overall excellence.

For further information contact **Valerie Brooke** by email: **vbrooke@saturn.vcu.edu** or by telephone: **(804) 828-1851**.



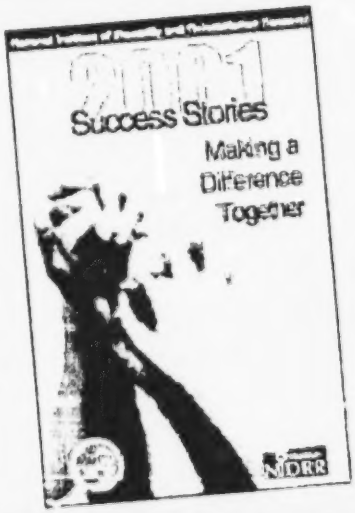

## Dissemination Self-Inventory

This revised version of the self-inventory is designed to help staff implementing research project designs, staff seeking to improve or expand their dissemination and utilization outcomes, and those who are developing new proposals involving dissemination and utilization functions. The inventory can be used by a single administrator or by all staff involved in project activities.

**On-line: http://www.ncddr.org/du/products/disseminv/index.html**

## Success Stories 2001

This issue in the series highlights a variety of "successes" realized by NIDRR-funded grantees in their dissemination and utilization efforts. In this issue, grantee successes are broken up into three areas: Highlights based on items reported to NCDDR by grantees, NIDRR Grantee and Staff Recognitions that were reported and included in NCDDR's *The Research Exchange*, and a Who's in the News section which focuses on media attention that was reported by grantees.




**On-line: http://www.ncddr.org/du/successstories/**

## How To Contact The National Center for the Dissemination of Disability Research

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1-800-266-1832 or 512-476-6861 V/TT
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*The Research Exchange* is available in alternate formats upon request.

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Volume 7 • Number 2 • 2002

THE Research Exchange

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This newsletter is available in alternate formats upon request.

SOUTHWEST EDUCATIONAL DEVELOPMENT LABORATORY
Building Knowledge to Support Learning

A project funded by the NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH
NIDRR

# Reaching Rural Communities:

## Increasing Access to Disability Research Information

If all NIDRR grantees used only the World Wide Web for distributing information, as much as 93 percent of people with disabilities living in rural areas would not be able to access the information, according to Dr. Tom Seekins, Director of the RTC on Rural Rehabilitation Services. In a recent NCDDR interview, Dr. Seekins pointed out the need for a variety of channels and formats to ensure that consumers with disabilities in rural areas are able to receive information. Seekins and several other NIDRR grantees whose projects focus on rural populations were invited by the NCDDR to share information about their research and their outreach and dissemination experiences targeting rural audiences.

The dissemination mission of the NIDRR community includes potential users of research outcomes from rural America. For some NIDRR grantees, people with disabilities living in rural areas may represent a population that is underserved and/or difficult to reach. Specific strategies to overcome existing barriers for people with disabilities who live in rural settings are addressed in this issue of *The Research Exchange*.

**For some NIDRR grantees, people with disabilities living in rural areas may represent a population that is underserved and/or difficult to reach.**

### Disability in Rural Areas

Studies of the demography of disability in rural America show that non-metropolitan areas have the highest percentage of people with disabilities, including people with severe disabilities. Data indicate:

- approximately 12.5 million of rural Americans have disabilities, and six million have severe disabilities,
- people with disabilities make up 23 percent of the non-metropolitan population, compared to 18 percent in metropolitan areas, and
- approximately 11 percent of the non-metropolitan population reports a severe disability; slightly higher than the nine percent reported for metropolitan areas (Seekins, Innes, & Maxson, 1998).

*continued on page 2*



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A Word from the Director

# Dissemination and Utilization for Rural Populations

Unlike many of America's past decades, more and more Americans are living in urban/suburban environments. Farming and agricultural vocations are employing fewer and fewer Americans. Although conducive to narrowing gaps that may be caused by geographical dispersion, Information Age technologies do not appear to be fully utilized to integrate rural populations. Most of the recent attention on universal access, physical accessibility and service delivery has been focused on meeting the needs within urban/suburban-based target groups of persons with disabilities in America.

While meeting the needs of urban/suburban Americans is essential, another significant group of Americans with disabilities reside within rural environments and present many, perhaps unique, challenges for service providers and those facilitating the dissemination and utilization of needed research-based information resources. Clearly, appropriate disability-related research outcomes need to find their way to people with disabilities who can use them, even though they may live in geographically remote or rural areas.

However, an important question remains regarding the extent to which research-based information is applicable or targeted to people with disabilities living in rural environments. Researchers may not consider characteristics of residency when establishing a research sample. The extent to which rurally-based people with disabilities are participants in a research design may go unmentioned, unless the research study is solely oriented to this target population. While it is generally accepted that most research designs and sampling techniques should randomly assign subjects according to race, ethnicity, and gender for generalization to the widest population base possible, much less clarity exists in regard to the characteristic of where a research subject may live. The ability of rural residents with disabilities to utilize specific NIDRR research findings may rest upon the degree to which the researcher was sensitive to including this group within the research process.

Research teams should also be aware of the way in which rurally-residing people with disabilities are integrated into Participatory Action Research (PAR) and project advisory activities. If research designs and dissemination/utilization activities are going to best fit the needs of rural Americans, their involvement in such participatory and advisory functions would be invaluable.

This issue of *The Research Exchange* highlights some ways in which selected NIDRR grantees have addressed some of these issues. These highlights may provide insights for other grantees that may be useful in adopting or adapting them within your research project and related dissemination and utilization activities. Additional technical assistance is available from the NCDDR for NIDRR grantees in planning and implementing rural outreach efforts.

*John D. Westbrook, Ph.D.*
*Director, NCDDR*

## Reaching Rural Communities

*continued from page 1*

Possible reasons for the disproportionately higher rate of disability in rural areas are delineated by Enders and Seekins (1999):

- Many rural occupations are among the most physically dangerous and produce high rates of injury that can lead to or result in disability.
- The proportion of older Americans in rural areas is higher than in urban areas, and rates of disability increase with age.
- Individuals who have attained higher levels of education tend to leave rural areas for employment in cities. This migration pattern leaves a higher proportion of less educated people working at dangerous occupations, potentially contributing to the higher injury rate.
- Medical and other support services that may help prevent disability are less available in rural areas.
- The infrastructure (such as public transportation and physical access to buildings) is less developed in rural areas and may contribute to reported limitation/disability.
- Poverty is often associated with disability, and poverty rates in rural areas are disproportionately high, equivalent to those found in U.S. central cities (p. 15).

### Barriers in Rural Areas

What are the barriers to dissemination of information to rural people with disabilities? Some of the factors that contribute to higher prevalence of disabilities in rural areas also create barriers to disseminating information in those areas. The limited development of the infrastructure of transportation and communications systems impacts information sharing. Greater numbers of older and less educated individuals hold implications for the format and content level of information that is appropriate for dissemination. Rural isolation can create communication barriers when the sources of information are people perceived as "outsiders." Other factors complicating dissemination may include limited health care facilities, few rehabilitation services, and economic hardship. Overall, there is limited awareness of disability research and its potential positive impact generally on the lives of people with disabilities in rural areas.

### NIDRR Grantee Experiences

The following articles present information from grantees describing their work within rural communities and strategies that may be useful for NIDRR grantees to use in reaching consumers with disabilities who reside in rural communities. Many of the strategies used and reported here by NIDRR grantees were helpful in overcoming some rural environment associated of the barriers. Other

strategies proved useful to gather information about the needs of rural people with disabilities. Some of the research using technology shows promise for ways to increase access to and ongoing communication with rural populations.

- **Roxanne Pickett Hauber, Ph. D., R.N.**, Manager and Nurse Researcher of the **Telerehabilitation to Support Assistive Technology** program at the Shepherd Center in Atlanta, talks about the use of telerehabilitation applications to provide follow-up support to recently-discharged patients, their families and their health providers. Implications and benefits of telerehabilitation applications for individuals from rural communities are discussed. Article on page 4.

- In an interview with **Tom Seekins, Ph.D.**, Director of the **Research and Training Center on Rural Rehabilitation Services (RTC:Rural)** at the University of Montana, NCDDR staff learned of the dissemination strategies used by the RTC:Rural in their efforts to reach rural communities. Among other dissemination formats, Dr. Seekins described the use of technology and the associated social and economic barriers that preclude many rural residents from the equitable use of technology. Article on page 6.

- **Ari Mwachofi, Ph.D.**, Principal Investigator, **Developing a Rehabilitation Service Delivery Model for Minority Farmers with Disabilities** at the University of Arkansas, talks about how personal contact, the development of trust, and collaboration with community leaders–all integral components to successful research and dissemination activities with rural audiences–facilitated their research project. Article on page 9.

- **Robert L. Glueckauf, Ph.D.**, Principal Investigator of **Home-Based Video-Counseling for Rural At-Risk Adolescents with Epilepsy and their Parents** at the University of Florida, shares some of their participant recruitment and information dissemination experiences from their project's research with teenagers who reside in rural communities across five Midwest and three Southeast states. Article on page 11.

**References:**

Enders, A., & Seekins, T. (1999). Telecommunications access for rural Americans with disabilities. *Rural Development Perspectives*, 14(3), 14-21.

Seekins, T., Innes, & Maxson. (1998). An update on the demography of rural disability (RTC: Rural Factsheet). Available: **http://ruralinstitute.umt.edu/rtcrural/RuDis/RuDemography.htm**

# What is Rural?

The concept of rural can have a number of meanings, and there is no universally accepted definition of the term. Rural and non-metropolitan areas are generally defined by exclusion; that is, areas that are not classified as urban and metropolitan are rural and non-metropolitan, respectively. Several criteria are used to define urban and metropolitan areas.

The Census Bureau differentiates between rural and urban areas. The U.S. Office of Management and Budget (OMB) uses the terms metropolitan and non-metropolitan areas. The Department of Agriculture's Economic Research Service employs various codes such as rural-urban continuum codes, urban influence codes, county typology codes, and rural-urban commuting area codes (Rural Policy Research Institute, 1999). The more commonly used definitions are those of the Census Bureau and the OMB.

In 1990, the Census Bureau defined urban areas as places of 2,500 or more persons and comprising all territory, population, and housing units in urbanized areas (with some exceptions). Territories and places that are not urban are considered rural. The 2000 Census Bureau criteria uses "the territory designated as urban clusters, rather than the entity of places that have a specified population, to determine the total urban population outside of urbanized areas" (U.S. Census Bureau, 2000, p. 4).

The OMB uses a county-based definition where metropolitan areas are those counties with one or more major cities of at least 50,000 people or with a Census Bureau-defined urbanized area with a population of at least 100,000. In addition, those outlying counties that are economically and socially connected to the county-based metropolitan areas are considered a part of the metropolitan area. Non-metropolitan areas or counties are considered rural counties (RUPRI, 1999).

For more information:

Rural Policy Research Institute (RUPRI). (1999). *Rural policy context.* **http://www.rupri.org/policyres/context/index.html**

U. S. Census Bureau. (2000). *Census 2000 urban and rural Classification.* **http://www.census.gov/geo/www/ua/ua_2k.html**

# Shepherd Center's Web-Based Learning Connections

***Roxanne Pickett Hauber, Ph. D., R.N.**, Manager and Nurse Researcher of the Telerehabilitation to Support Assistive Technology program at the Shepherd Center in Atlanta,* *talks about the use of telerehabilitation applications to provide follow-up support to recently-discharged patients, their families and their health providers. Implications and benefits of telerehabilitation applications for individuals from rural communities are discussed.*

NIDRR has provided leadership in redefining disability as "the product of an interaction between characteristics of the individual and characteristics of the natural, built, cultural and social environments" (Seelman, 2000). Within this new paradigm of disability one must consider:

- What is in an environment?
- Is it accessible and available to everyone?
- And if not, how can it be modified so that it will be universally user-friendly?

The new cyber-environment lends itself to being modified, even customized to the user so that resources and services are readily accessible. For that reason, cyber-environments have tremendous potential for changing the world for people with disabilities (Vesmarovich, Hauber and Jones, 2000). The use of these advances in telecommunications technology to inform and educate has resulted in the emerging field of interactive health communication (IHC) (Hauber, Vesmarovich and Testani-Dufour, in press).

In 1999, Shepherd Center in conjunction with Georgia Institute of Technology and corporate partners, Bell South, Cyber-care, and Siemens, Inc. were awarded a matching funds grant from the U. S. Department of Commerce National Telecommunications and Information Administration to develop a Next Generation Internet (NGI) network in the metro-Atlanta area linking patients' homes and rehabilitation service providers. Georgia, in general, is a rural state with a few major areas of urban concentration. Primary care clinicians cover the state reasonably well, but rehabilitation expertise for people with brain and spinal cord injury is limited to the major urban areas (Stachura, 2001). Therefore, mechanisms that can empower individuals with related disabilities and their families living in rural areas are crucial to optimize long-term outcomes.

Part of this project included the development of a server database that included disability-specific health and wellness information addressing patients' specialized care needs. This information is used to deliver, over the network, "just-in-time" interactive, multi-media instruction and support to patients and caregivers. The materials provide easy access to essential information about specific health care routines, community resources, and topics related to moving beyond disability such as travel, healthy life styles, recreation, and return to work and school. These instructional and resource materials can be accessed in the home, at work, at public libraries, in small clinics and anywhere people have access to the Internet.

**"...cyber-environments have tremendous potential for changing the world for people with disabilities."**

Prior to beginning this endeavor, a three-year retrospective survey of Shepherd patients was conducted to find out what percentage of our clients has access to computers and the Internet. Findings indicated that 73% of individuals surveyed had access to and used computers and 68% had access to the Internet (Hauber et al., in press). The survey also asked participants what types of health-related information they had found on the Internet that was useful, and what kinds of things they had not been able to find, but would like to have access to on the Internet. In addition, a consumer group made up of former Shepherd patients was initially brought together to discuss the kinds of information, resources, etc. they would find useful. Guidelines from the Science Panel on Interactive Communication and Health (1999) were used as the materials were developed.

All patients who receive rehabilitation services at Shepherd and their families are instructed on how to access and use the materials while they are in in-patient rehabilitation. To access this material go to Shepherd's website **http://www.shepherd.org/** ; Select *My Vital Connections*, choose *Patient Pages*, and then click on *Preview Page*.

# Access to Disability Research Information by Rural Consumers:

## Key Findings from the NCDDR 2001 Survey

**Author Notes:**

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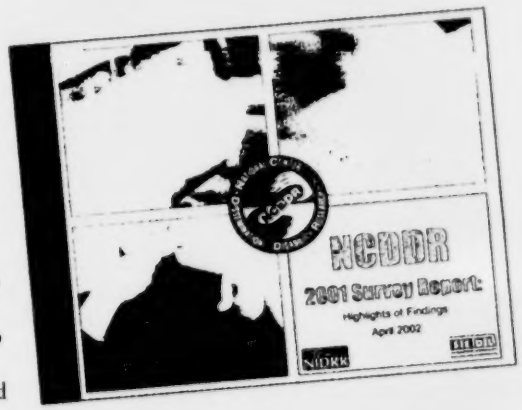
The NCDDR engages in an annual survey activity to help increase the knowledge base in the NIDRR community regarding the dissemination and utilization (D & U) of disability research findings. The survey focuses on obtaining information across major groups invested in disability research. A key component of the survey activity is to gain knowledge about what areas of disability-related research are important to consumers, how consumers prefer to receive disability research information, and how the use of computers and the Internet/Web are helping consumers' search for information. The knowledge gained helps to inform researchers from the NIDRR community about ways consumers with disabilities and their families obtain and use disability research information.




Survey participants included individuals with disabilities, representatives from organizations that focus on more direct consumer contact, and NIDRR-funded grantees). The consumer group consisted of people with disabilities and their families who participate in Independent Living Centers (ILCs) across the country. Following are some key findings from the *NCDDR 2001 Survey* concerning consumers with disabilities from rural areas and their information needs.

### Demographics

- Thirty percent of the respondents reported they were from rural areas.
- The majority of rural respondents were female, aged 30-49 years, White, and had a physical/orthopedic disability.
- Thirty-one percent reported being employed full-time, while 23 percent reported they were unemployed and not seeking employment.
- Receiving information in English was preferred by the majority of rural consumers.

### Disability Research Interests

- Rural consumers were most interested in research on independent living and community integration, followed by interest in research on legal/policy issues, research on assistive technology, and research on employment.
- Ninety-three percent of rural consumers agreed that disability research is useful, but fewer agreed (48%) they could easily find disability research.

### Accessing Disability Research Information

- Rural consumers reported they contacted a community service provider/disability advocate most often (70%) when obtaining disability research information. Other approaches used to obtain information included calling a disability-related organization (64%); looking in brochures, fact sheets, or newsletters (56%); looking on the Internet (52%); and looking in research journals (25%).
- The majority of rural consumers (87%) preferred receiving disability research information via printed materials. Other preferred formats for receiving information included telephone/toll-free information line (78%); Internet/Web or e-mail (73%); pictures (62%); videotape (59%); and audiotape (54%).

*continued on page 20*

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Hauber, R. P., Vesmarovich, S., & Testani-Dufour, L. (in press). The use of computers and the Internet as a source of health information for people with disabilities. *Rehabilitation Nursing.*

Science Panel on Interactive Communication and Health. (1999). *Wired for health and well-being-the emergence of interactive health communication.* Washington D.C.: U.S. Department of Health and Human Services, Office of Public Health and Science.

Seelman, K. D. (2000). *Science and technology: Is disability a missing factor?* Colin McLaurin Distinguished Lecture sponsored by Sunrise Medical, RESNA, Orland, FL. July 1, 2000.

Stachura, M. E. (2001). The Georgia state-wide telemedicine network: some lessons learned. *Journal of Telemedicine and Telecare.* 7(suppl.2) 62.

Vesmarovich, S. H., Hauber, R. P., & Jones, M. L. (2000). Using telecommunication technologies to change the world for people with disabilities related to catastrophic neurological impairment. *Cyberpsychology and Behavior.* 3(6) 925.

# Outreach Strategies of the RTC on Rural Rehabilitation Services

*In an interview with* ***Tom Seekins, Ph.D.****, Director of the Research and Training Center on Rural Rehabilitation Services (RTC:Rural) at the University of Montana, NCDDR staff learned of the dissemination strategies used by the RTC:Rural in their efforts to reach rural communities. Among other dissemination formats, Dr. Seekins described the use of technology and the associated social and economic barriers that preclude many rural residents from the equitable use of technology.*

**NCDDR: How does your project disseminate disability research information to consumers in rural/remote areas?**

**Seekins:** As a national research center, we don't typically provide a lot of direct services. We are often in direct and intimate connection with consumers, people with disabilities, when we are working together on research projects designed to develop innovative practices. So, for example, one of our programs is a health promotion program called *Living Well With a Disability* that we've done around the country, working through rural centers for independent living. Well over 300 people with disabilities have participated in that and received services. So, in the sense that individuals with disabilities are participating in a research project that is designing or developing a new service model or new service program, we're in direct contact with consumers and providing them information and services.

Once the research is completed, our goal becomes broad dissemination of the findings and, when appropriate, broad adoption of the innovation. We use several strategies to accomplish that goal but the one that comes closest to reaching consumers involves targeting our dissemination of the information that we gather, the findings, and the products that are developed from that research to what might be called intermediaries, that is service providers, support systems or networks. While the information that we develop from our research and other sources is available to individuals and we do provide information to some individuals, we believe our greatest impact comes from our research changing the way programs and service providers operate. Our perspective is that those networks are in place and their role is to reach the broad population. If they view our information and products as valuable, they will integrate them into their programs.

**"...we believe our greatest impact comes from our research changing the way programs and service providers operate."**

We disseminate information directly to the intermediaries in a couple of different ways. One is an electronic email distribution system that sends out, about once a month, research progress reports, rural practice guidelines and a series of brief fact sheets that summarize a finding or some important policy change or something that's going on that has implications for rural areas. A single paragraph abstract describing these information pieces goes out electronically with a Web site link for each, so that if the intermediaries read the electronic abstract and are interested in it, they can click on the specific Web site link and read more about the topic. We also have much more detailed information on these Web sites including further links to other resources.

It's important to say that we recognize that access to and use of the Internet in rural areas is much lower than in urban areas. So, in addition to the electronic system, we still maintain an actual mailing list used to send out the same information in hard copy as well. We don't feel that this is redundant. In fact, we look at it as using two different channels of communication for each of our messages.

In terms of a specific audience, what we have designed is a system that permits us to be very targeted in what we do disseminate and to whom we disseminate the information. We don't disseminate all the information we have to everybody on the mailing list. Depending on the content of the fact sheet or other information piece, we target our mailing to the constituent and intermediary groups that are really going to be interested in that particular topic.

One of the other important things that we have tried to do is use the media. A study on media and disability conducted by Cyndi Jones of the Disability and Rehabilitation Research Project to Disseminate Independent Living Research Information Through the Mass Media to Persons with Disabilities **http://www.accessiblesociety.org/** in San Diego found that most people with disabilities get most of their information about disability from mainstream media. And so, we took that to heart and tried to address the question, what media is most used in rural communities? There are two media

formats that we're trying to target. One is the use of small town and rural county newspapers. We have developed a mailing list of those around the country and we send them all of the information that we develop. We are also going to try to target the rural radio as well. For a lot of rural areas, radio is an important source of information. Unfortunately, we have not had the time or resources to evaluate the impact of this effort yet.

**NCDDR: Who are some of these intermediaries that your project networks and collaborates with to help move disability research information to consumers in rural/remote areas?**

**Seekins:** We have a list of about 36 different national service, advocacy, and support networks that do significant or substantial work in rural areas. So, for example, the Association of Programs for Rural Independent Living (APRIL) is a national association of Independent Living Centers that work in rural areas. The APRIL group is one network out of 36. There are 178 members of that group and probably about 120 of those are actually Centers for Independent Living. Our research shows that those programs serve over 25,000 individuals with disabilities living in rural areas annually. So, by targeting those 120 CILs, we hope to reach 25,000 people indirectly.

The 36 networks consist of major categories such as the Administration on Developmental Disabilities, American Indian Programs, the National Association of Protection and Advocacy Systems, and the National Rural Health Association, to name a few. These are further divided into different targeted groups.

Then we have the mailing addresses for all the regional and local vocational rehabilitation offices. It took us quite a while to develop this national listing of 1,235 vocational rehabilitation offices. We wanted to make sure that the contact persons receiving our information were vocational rehabilitation counselors who provide services directly to consumers. So, our information is reaching at least one contact person from 1,235 vocational rehabilitation programs that are working in rural areas. And so, that becomes an intermediary.

**NCDDR: How successful are your dissemination strategies?**

**Seekins:** One of the things we've tried to do in a couple of different cases is some systematic evaluation of satisfaction with the information that is provided. And we've run into a couple of problems with that. One is that when we have generic questions about satisfaction with materials that are distributed, they're not very meaningful questions because the information is too general. And so, the data we get back when we've asked generic questions have not been very useful. When we try to be more specific, the questions get so specific that we don't get very many responses. So, the combination of those two factors has led us to rely primarily on what we call spontaneous feedback.

What will happen, for example, is that we'll electronically send out a fact sheet on rural mental health issues and within the first week that it has been disseminated, we will have received a half a dozen responses electronically from some relatively well-known program directors and policy makers. Their feedback basically says thanks, this information is wonderful, send us some more, and how can we find out some more about this topic. That's one way we determine the utility of the information. We look at the number of comments we receive, the quality and content of the comments, and try to use that information to really shape what we disseminate in the future. It would be really nice to have more detailed evaluations of our dissemination activities, but the expense associated with evaluating it in terms of the funds we're able to allocate across all of our projects is more than we can afford at this point.

What I can say, however, is that we can point to a broad range of impacts–changes programs have made in the way they go about their work–associated with the dissemination of our research. While that's the bottom line, we think we can do better and evaluation would help. It's just that we've chosen to invest our evaluation resources in the development of the research.

**"...we can point to a broad range of impacts associated with the dissemination of our research."**

**NCDDR: How does your project include consumers from rural/remote areas as participants in a research study?**

**Seekins:** We believe we have a strong program of Participatory Action Research. Involvement varies pretty significantly depending on the topic or the issue we're trying to address. We tend to look at our constituents or the potential users of our research as not just people with disabilities, but also people who are those intermediaries, both from Centers for Independent Living, from rehabilitation programs, from Section 21 programs, or whoever they may happen to be. So, when we start off looking at a research project, we actually look at topics. We try to identify ahead of time research topics that are going to lead to programs that will have systems change effects. That is, changing the way that systems operate and are organized to be more conducive to promoting quality living for rural residents.

So, in the transportation program, for example, we worked very closely with staff and consumers of Centers for Independent Living and other kinds of community-based service programs, including developmental disability service programs to design and craft the program. When we went out to do the research, we worked with people representing those kinds of service networks. We worked with them to design and implement the model and facilitate the research and evaluation of the model. We collaborated on making modifications and designing something that would fit within the context of those service programs. Then, once we got it to a point where the research and evaluation showed that it was an effective model, we looked for ways of replicating it for wider use. In this case, APRIL secured a grant from the Rehabilitation Services Administration to demonstrate the utility of the program in ten states. The goal of this step is to demonstrate a program that can be sustained locally. In this way, the services eventually get to individuals with disabilities thus increasing their access to independent living, employment, and education

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Outreach Strategies of the RTC
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opportunities, areas to which they may not have had access earlier because of the lack of transportation.

**NCDDR: What are some issues related to rural communities and access to telecommunications?**

**Seekins:** A study Alexandra Enders did in collaboration with Dr. Stephen Kaye of the Disability Statistics Center at the University of California in San Francisco looked at the distribution of individuals with and without a disability who own a computer and use the Internet in metropolitan, suburban, central city and rural areas. The study found that people with disabilities who live in rural areas were less likely to own computers when compared to people with disabilities who live in metropolitan, suburban, and central city areas. This is a pretty consistent finding and similar to findings that disaggregate metropolitan areas into central city and suburban areas and then look at non-metropolitan or rural areas. Non-metropolitan areas and central cities have much more in common with each other than either has with suburban areas in the nation.

**"...the percent of individuals who own a computer with no disability in central cities is about 47.4 percent. In rural areas it's 44.5 percent..."**

For example, the percent of individuals who own a computer with no disability in central cities is about 47.4 percent. In rural areas it's 44.5 percent, so, you can see some similarity. In suburban areas, computer ownership is 58 percent. The percentage of individuals with a disability who own a computer in suburban areas is almost 30 percent compared to approximately 20 percent in central cities and rural areas.

Then, if you look at the percent of individuals who use the Internet in urban and rural areas and you look solely at people with disabilities, only 6.8 percent of the people in rural areas who report a disability use the Internet. So, it's somewhere around a third of the people who have a computer are accessing the Internet. That means that about 93 percent of people with disabilities who live in rural areas do not use the Internet at this time. This has obvious implications for electronic dissemination practices.

Also, when you look at the demographics of income levels, poverty rates in rural areas are very, very similar to those in central cities, overall. A lot of people don't have that perception and understanding. They tend to look at rural areas as these bucolic areas of rolling farmlands and big families and happy times. There are a lot of myths that are invested in these kinds of concepts of rural living. But the reality is that rural areas are often very poor areas with disability prevalence rates that are higher than in urban areas.

Issues with access to telecommunications also include significant infrastructure problems that exist in rural areas. A couple of years ago, and you still see this from time to time, ads appeared in major metropolitan newspapers that said "sign up with blank Internet service, free access." If you read to the bottom of the advertisement, you'd see further information in small print "except in outlying areas that are difficult to access." Basically what those ads were saying is that if you live in a city, you can access the server free, but if you live in a rural area, you probably have to pay, not only a long distance call charge, but you may have to pay some other access fees. This presents an economic barrier to many rural residents.

In terms of the infrastructure, one of our staff, Alexandra Enders lives north of Missoula on a reservation, and she actually does a lot of work in telecommunications for our center. Although she owns a computer with access to the Internet, she has to drive in to the office to access the Internet. If she were to try to connect to the Internet from her home, it's a long distance telephone call to the server. And not only that, the quality of the cable infrastructure in her area and in a lot of rural areas is poor, still copper wire, which means that Internet access is extremely slow. The slow Internet access just means the cost will be even higher, since she's paying a long distance charge to access the Internet in the first place. So, despite the availability of the computer and Internet on her end, access to such telecommunications is a barrier due to the inadequate cable infrastructure.

There are a lot of national and state efforts to improve the infrastructure in rural areas for telecommunications. I think a sort of historic parallel to that might be like the rural electrification process during the early parts of the last century when there was a concerted federal effort to try to extend electricity services out into the rural areas of the country and later, on the heels of that, phone services. Cities and metropolitan areas all have the infrastructure much earlier than the rural areas and very similar kinds of processes are happening with the Internet and other types of telecommunications. But for the foreseeable future direct access to the Internet for information, services, and training for people with disabilities in rural areas is pretty limited.

We are presently conducting a study of Internet access and use for various service activities by rural centers for independent living. The surveys are literally out in the field and we're just starting to receive the data. In the past, we have been able to estimate that most centers for independent living serving rural areas do have computers and most do have access to the Internet.

However, there are a whole series of questions that have not been adequately answered. Questions like how many computers do they have? How many accounts do they have? How many staff has access to the Internet? How easy is it for them to get access to it? What's the capacity of their staff to locally use the potential capacity of electronic-based systems of computers and Internet, and even e-mail, for service delivery?

I think it's fair to say that the promises and declarations that are often made concerning how the use of the Internet or other telecommunications will be a boon for people with disabilities who live in rural areas,- are not yet true by any stretch of the imagination. Right now, it's a vision for the future. If those visions come true, there will be some substantial benefits. But right now it's just not the reality.

**NCDDR: What general recommendations can you make to assist in guiding other NIDRR grantees in their efforts to disseminate information to rural audiences?**

**Seekins:** We recommend working with systems or intermediary organizations. Given that we work in disability and rehabilitation under the Rehabilitation Act, we tend to view our "core constituency" as those systems in the Act. There are other systems that directly reach people with disabilities or that support those who do. If you have research that is valuable to them or their consumers, they provide a fantastic channel for dissemination. Better yet, if you have interest in research relevant to rural areas, use PAR approaches to work with those systems to design and conduct the research. That increases the likelihood that the results will address important issues, do so in appropriate ways, and produce significant outcomes. If your research meets those criteria, there's a good chance it will be adopted.

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For more details on studies mentioned in this interview see:

Rates of computer and Internet use: A comparison of urban and rural access by people with disabilities
http://ruralinstitute.umt.edu/rtcrural/TelCom/computer.htm

News coverage of disability issues
http://www.accessiblesociety.org/topics/coverage/

# Strategies for Building Communication and Participation:

## Experiences from the Lower Mississippi Delta States

***Ari Mwachofi, Ph.D.**, Principal Investigator, Developing a Rehabilitation Service Delivery Model for Minority Farmers with Disabilities at the University of Arkansas, talks about how personal contact, the development of trust, and collaboration with community leaders–all integral components to successful research and dissemination activities with rural audiences–facilitated their research project.*

### Background

The observations and suggestions presented here come from the experiences of a participatory action research (PAR) project, *Developing a Rehabilitation Service Delivery Model for Minority Farmers with Disabilities.* The purpose of the project is to build a dynamic and effective model of service delivery to minority farmers who have traditionally been underserved. The study involves farmers (rural residents) from the Lower Mississippi Delta (LMD) states–Arkansas, Louisiana, and Mississippi.

### Dissemination strategies used to inform and recruit participants

The project began with a great deal of publicity informing farmers about the project's objectives so they would be prepared to meet with the project staff for interviews. Combinations of strategies were used to effectively disseminate the information. Strategies included use of the media, selection of key project staff, creating farmer-to-farmer referrals building farmer teams, contacting rural churches, collaborating with farmer organizations and agencies that work directly with farmers. The following are descriptions of strategies used to disseminate information about the project, recruit participants, and gather data for the research study.

#### Use of local media

Small locally-oriented newspapers were targeted to promote awareness about the project. These newspapers were more receptive and willing to publish articles than were the larger newspapers. Residents of small rural communities responded to these articles by requesting more information about the project. Articles were also published in rural newsletters such as *Farm Sense* and other farmers' cooperatives newsletters. These were especially effective because they targeted a particular audience of rural farmers. On occasion, the larger newspapers picked up the story about the project after it was published by the local newspapers. For instance, on 12/21/2001, *USA Today* published an article about the project after it had appeared in the local *Pine Bluff Commercial* newspaper. This provided the project with national publicity thus increasing awareness and willingness on the farmers' part to participate in the project.

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### Collaboration with community leaders and local organizations

Staff contacted agencies that work directly with farmers such as the Cooperative Extension Service, Farm Service Agency, Natural Resource Conservation Service, and state vocational rehabilitation agencies in the three states. Letters were written to local community groups, farmers' cooperatives, churches, and farmer organizations such as the Black Farmers and Agriculturalists Associations, Southeast Arkansas Vegetable Growers Association, and other vegetable association cooperatives and farmers' cooperatives across the three states. These organizations were asked for assistance in disseminating information about the project and the research process to their members. Phone calls, meetings, and direct mailings were part of the information dissemination process. Other farmer-related organizations targeted included the Small Farm Projects at Southern University in Louisiana and at Alcorn State in Mississippi. This dissemination process proved to be effective because farmers soon began to call our project staff for more information.

### Use of informal networks

In order to locate the most underserved farmers, the project went to rural churches, community groups, farmers' cooperatives, and other farmers' small organizations. Farmer-to-farmer referrals, where the farmers we talked to referred us to other farmers, were used and helped in building farmer teams to participate in the project. This was probably the most effective method because it also helped build the farmers' trust and willingness to communicate with us. Building of the farmer teams consisted of contacting active and influential farmers in the community, providing them with relevant project information, and emphasizing the benefits of the research for the participants. Once these key farmers understood the purpose of the project, they talked to other farmers about it. Community groups ranging from five to 20 farmers were formed. The project staff then set up informal meetings–we have learned that informal meetings work best when communicating with farmers–to further clarify project objectives and to recruit participants. Farmers with disabilities who were unable to join us at the community meetings were contacted in their homes where one-on-one interviews were conducted.

### Use of researcher who is familiar with the culture of the target population

Perhaps the most useful strategy was the recruitment of key project staff. After a very slow start working with research assistants from academia, the project recognized the need to have a research assistant who understood the farming community. The project recruited and trained a female farmer who had been running a successful farm for the past 20 years and was preparing to retire from farming. She proved to be the greatest asset to the project. Her practical approach to the research study helped the farmers understand and be comfortable with the process of providing information via surveys and interviews. She brought to the project an understanding of farmers and how they operate and think. Not only did she know the best strategies to get farmers' attention, she knew many farmers and farming communities in Arkansas.

### Development of trust through personal contact

The building of trust with the farmers was perhaps the most formidable challenge. Even after we found the farmers, we had to build their trust in us before they agreed to talk to us. In order to build that trust we resorted to unconventional interview methods. Farmers selected the meeting sites and we worked around their schedules. A very effective approach was to meet them in very informal situations. For example, after making contact with a key farmer who then contacted a group of farmers, a meeting would be set up in a local restaurant or at an outdoor evening cookout. This provided an informal and relaxed atmosphere. Farmers asked as many questions as necessary, and if willing, would fill out the questionnaires at the meetings. The assistance provided by the key individual farmers in organizing the farmer teams helped the project staff build the trust necessary for the success of the research project. Without them, the project would not have been able to get the farmers to respond to the survey questions.

**"Even after we found the farmers, we had to build their trust before they agreed to talk to us."**

### Barriers to overcome

A difficult barrier for the project was locating the farmers to participate in the study. A comprehensive list of the farmers and their contact information was not available. Some of the agencies that serve farmers had lists of those farmers they serve and for legal reasons were not willing to share their lists. In any case, if we used their lists, we would be excluding the very farmers we wanted to talk to the most, that is, those who were not being served. In order to get a large enough sample of minority farmers, we used stratified random sampling. We focused on counties that had at least ten farmers who were minorities. From the 1997 Census of Agriculture statistics, the project located thirty-one such counties in Arkansas, 65 counties in Mississippi, and 42 parishes in Louisiana. The goal was to interview 200 farmers in each bringing for a total sample of 600 farmers.

### Responding to the survey

Another challenge was the task of getting farmers' responses to the survey instrument. We found that a large number of farmers had genuine literacy difficulties and others just did not feel comfortable reading and/or writing. This problem was made more complicated by the length of the survey instrument and the personal nature of the questions. In an effort to overcome this problem, several methods were incorporated to obtain data. The most effective method consisted of going out to the field with student researchers who read the questions and recorded the farmers' responses on the surveys. Questions were also read to small groups of farmers and they, in turn, wrote their responses on the survey instrument.

### Mistrust

The project found that farmers do not trust people from outside their communities. They become even more distrustful of any project that is even remotely connected to the government. The personal nature of most of the survey questions compounded this problem. The farmer teams used in the research process were essential in alleviating the farmers' mistrust of the project.

### Racial issues

This is one challenge that we are still trying to resolve. Since we are from a historically Black university, we had difficulties getting white farmers to talk to us. On some occasions, we succeeded in meeting with them and obtaining survey responses from them. However, we are still trying to find ways to build an effective network with this

group of farmers. A possible idea that we may use in the future is emphasizing the similarities of the problems faced by the farmers, regardless of their racial status. The project intends to use these similarities as a way to promote the participation of white farmers.

### Stage two of the project

In the second stage of the project, we are interested in learning about the farmers' perceptions and their recommendations on the best ways to serve them. Using lessons learned and the networks developed during the first stage, we changed our interview approach. In an effort to avoid the paperwork and mistrust issues experienced in the first stage, we decided to get the farmers' views through focus group discussions. Using the already established networks, we returned to the communities and located some influential and well-respected farmers. We trained 13 farmers (five in Louisiana and four each in the other two states) to facilitate focus group discussions with farmers in their communities. The purpose of these meetings was to gather the farmers' views about service delivery purely from their perspective without any outsiders' influence, thereby increasing opportunities for open and free discussions and decreasing mistrust.

The 13 farmer facilitators are in the process of conducting focus group meetings. So far (May, 2002), there have been 16 focus group discussions involving 216 farmers in the three states. The first stage survey results informed us that farmers generally have little knowledge about vocational rehabilitation services. As a result, we decided to combine outreach with stage two of the project. At the end of each focus group session, an agent from the state vocational rehabilitation agency provides information to the farmers about the agency's services. Thus, the focus group sessions serve several purposes: gathering feedback from the farmers, stimulating farmer participation in our research, and educating farmers with and without disabilities about vocational rehabilitation services in the state.

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# Home-Based Video-Counseling for Rural At-Risk Adolescents with Epilepsy and Their Parents

***Robert L. Glueckauf, Ph.D.**, Principal Investigator of Home-Based Video-Counseling for Rural At-Risk Adolescents with Epilepsy and their Parents at the University of Florida, shares some of their participant recruitment and information dissemination experiences from their project's research with teenagers who reside in rural communities across five Midwest and three Southeast states.*

### Project Background

Teenagers with epilepsy are likely to confront a variety of psychosocial and educational difficulties in coping with their medical conditions. Adolescents with seizure disorders are at a greater risk for developing psychological and school-related problems than are other teenagers with chronic disabilities as well as those without disabilities. Although advocacy organizations have called for the development of family counseling programs to address these difficulties, there continues to be a substantial gap between consumer needs and availability of epilepsy-related family services. The most damaging effect of this shortage of services can be found in rural areas, where local resources are limited and transportation to major medical centers poses severe obstacles to adequate specialty care. Counseling services for teenagers with epilepsy and their parents in rural America are at best inadequate and in most cases nonexistent (Glueckauf, Whitton, & Nickelson, 2002).

The primary purpose of this NIDRR-funded study is to assess the differential effects of *videoconferencing-based* versus *speakerphone-based* versus *face-to-face family counseling* on the psychosocial and educational functioning of at-risk rural teenagers with epilepsy. The intervention consists of six sessions of issue-specific family counseling provided in one of three service delivery modes: (a) home-based, video family counseling (VFC); (b) home-based, speakerphone family counseling (SFC); or (c) office-based family counseling (OFC). This multi-site investigation is still in progress and involves over 75 families of teenagers with seizure disorders who reside in rural communities across five Midwest and three Southeast states.

The first phase of the study involved participants from rural areas in five Midwest states: Indiana, Ohio, Kentucky, Illinois, and

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Michigan. A total of 39 rural Midwest families were recruited over a period of two years to participate in the project. Twenty-two teenagers with seizure disorders, 14 males and eight females, with a mean age of 15.4, and their parents (n = 36) completed Phase 1 of the project. The most cited reason for participant dropout was transportation problems (e.g., no vehicle and/or long distance travel would add wear and tear on their only vehicle).

Phase 2 of the study includes participants from rural areas across three states: Southeastern Alabama, Southern Georgia, and North and Central Florida. Phase 2, which includes an additional 36 families, is a replication of the Phase 1 study and will be completed by the end of the year.

## Outreach strategies used to recruit participants

The following strategies were used to recruit participants for both phases of the study:

- Research project information was distributed via mass mailings of fliers and information packets to school counselors and nurses in middle and high schools in the rural areas. This strategy was the most successful format used to recruit participants for Phase 1 of the study. School counselors were responsive to the request for project participants and facilitated the distribution of the project information to the targeted adolescents. This strategy, however, did not prove as successful for Phase 2 of the study. One reason for the limited response to fliers and information packets may lie in the centralized control of research initiatives in Florida secondary schools, our primary recruitment target. Although we received approval for the project from the Florida Department of Education authorities, there were periodic inquiries from school administrative staff about the need for state authorization before information could be disseminated to prospective participants. Note that there were no such inquiries from Midwest rural schools in Phase 1 of the study.

**"...Newspaper advertisements, television public service announcements and radio public service announcements were also considered successful formats."**

- Print and other media were also used to recruit rural teens with epilepsy and their parents. Although a limited project budget precluded extensive use of these formats, newspaper advertisements, television public service announcements, and radio public service announcements were also considered successful formats for recruiting research participants for both Phase 1 and Phase 2 of the study.

- An additional participant recruitment effort included letters submitted to patients at neurology clinics. For Phase 1, letters were sent from Indiana University's Riley's Children Hospital to prospective rural teen-agers with seizure disorders and their families. This proved to be the least successful format used to recruit participants for Phase 1 of the study. Lack of personal contact to the patients may have been the reason for this recruitment effort's lack of success.

- However, letters sent to patients was the most successful format used to recruit participants for Phase 2 (Southeastern states of FL, GA, and AL) of the study. Letters were sent from the Division of Pediatric Neurology, College of Medicine at the University of Florida to adolescent patients who were enrolled at the Pediatric Neurology epilepsy clinic. Following the mailing of the letters, personal invitations to participate were made via telephone calls by research staff from this regional clinic.

## Dissemination strategies used in informing rural population about project's work

The University of Florida Center for Research on Telehealth and Healthcare Communications, where the NIDRR project is currently housed, deploys a variety of strategies to inform rural consumers with disabilities about Center projects. Primary recruitment approaches include: (a) family forums at rural community centers, and (b) distribution of project brochures and fliers at local health departments, support groups, consumer organizations, and child service agencies. We also have created project CD-ROMs for distribution across several venues, including caregiver forums, schools, countywide jamborees, and rural conferences.

## Dissemination of project research outcomes to participants from rural communities

Preliminary research results were published twice yearly in project newsletters. The newsletters were written in lay language to enhance readability and comprehension. Several families responded with notes of gratitude.

## Barriers in dissemination and outreach strategies

A significant barrier to recruitment of research participants was the project's requirement that all families drive to the initial assessment session located at Dr. Glueckauf's university-based intervention suite. The principal investigator and project staff felt that due to the experimental nature of the study, it was ethically and therapeutically necessary to meet each family face-to-face before randomly assigning them to a home- or office-based counseling intervention. This would assure that the teens with epilepsy and family members had at least one direct personal contact with project counselors and research staff before counseling was initiated. A $60 honorarium and food coupons were provided to each family to defray the costs of travel. Unfortunately, despite our positive intentions, approximately 30% of families who expressed an interest in participating in the project did not attend the first assessment and subsequently, dropped out from the study. In future telehealth studies with rural populations, we plan to conduct the initial assessment session at the family's home to reduce pre-intervention attrition.

For more detailed information on this project, see the Special Focus Section on Telehealth and Chronic Disabling Conditions of Rehabilitation Psychology, Volume 47, Issue 1, February 2002.

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# Implications:

## Targeting Dissemination and Utilization to Rural Residents with Disabilities

Given the previous comments from NIDRR grantees, what does this tell us about dissemination and utilization to rural residents with disabilities? The following are implications that may be helpful in planning and implementing dissemination efforts that are targeting people with disabilities in rural environments:

**1. Ensure that the information to be shared has been targeted appropriately to rural residents with disabilities.**

Due to the differences in environmental infrastructure in rural environments, special considerations in your "message" would appear to be warranted in some cases. Establish that the message you are offering is targeted especially to "FIT" rurally-based people with disabilities.

**2. Format or tailor your message appropriately to "fit" the known characteristics of rural residents.**

Some evidence would tend to indicate that people with disabilities in rural environments might be less well educated than some of their more urban/suburban counterparts, therefore, tailor your message appropriately. Be aware of language usage and reading level in stating and communicating your message.

**3. Do not assume that electronic formats will comprehensively reach rural residents with disabilities.**

Data indicates that rural populations exhibit higher rates of poverty than in central cities. Do not assume that rural residents have access to computers, email, online Internet services, and World Wide Web resources.

**4. Utilize multiple formats for communicating your message, especially those that currently actively network with rural populations.**

Identify rural media outlets that target the area(s) you are trying to reach. Rural newspaper and radio media can be effectively used in rural outreach to people with disabilities.

**5. Identify associations, organizations, or groups that are currently networking rural residents and use them as an informational outlet.**

Data indicate that rural residents represent higher than expected rates of disability. Reaching into existing rural networks can be effectively in reaching target audiences within the rural population.

**6. Use social networks as a way to spread targeted messages.**

Churches, schools, and businesses can be centralized sources to reach many rural residents. Use these to target information that can be used specifically by rural residents with disabilities. Enlist their assistance in reaching others that may be in need of the information.

**7. Avoid establishing "conditions" that must be met by rural residents to receive needed information.**

Evidence indicates that rural residents exhibit high rates of poverty. Establishing costs with the receipt of information, no matter how reasonable, will establish a barrier between the intended recipient and the needed information.



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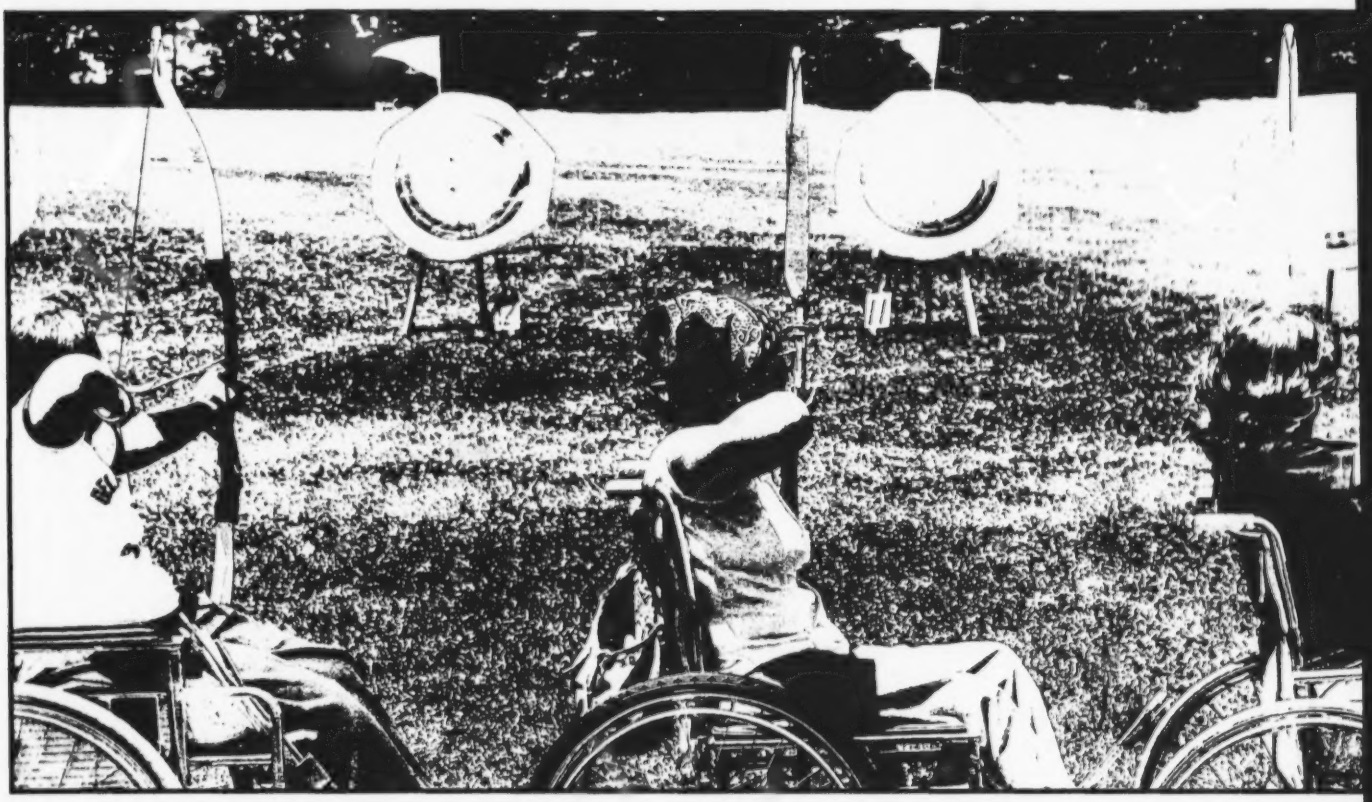

Implications
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**8. Be aware that cultural diversity characteristics should influence your rural information dissemination efforts.**

Trust can play a major role in how credible and reliable your "message" and its source are perceived to be. Be aware that cultural differences can play a part in these perceptions and maximize ways in which within-group dissemination can be organized and supported by your efforts.

**9. Be sensitive to age-related issues of rural residents including those with disabilities.**

Data indicates that rural residents tend to be older than their urban counterparts. Your dissemination efforts and selection of formats for communicating that information should recognize age-related needs in addition to disability-related needs.

**10. Recognize that transportation issues exist with rural settings and minimize the need for physical transportation.**

Assuming that rural residents with disabilities and their families can congregate in situations requiring transportation may not be accurate. Due to the infrastructure of most rural environments such transportation requirements in a planned information dissemination activity would seem to inhibit participation.

**11. Involve rural residents with disabilities in multiple aspects of your research activities – such as in Participatory Action Research (PAR) – in order to facilitate your dissemination.**

The use of PAR and other participation enhancing activities will increase the "fit" of your research with the intended user audience. Involving rural residents with disabilities in this process will make utilization easier and appropriate dissemination channels clearer.

**12. Ask for feedback from rural residents with disabilities not only about your information but also your dissemination strategies.**

Recipients of information are easily able to tell you what they think of what you have to share with them for use. In addition, they are generally more than happy to tell you how easy or difficult it was to access or receive the information.

This information should be valuable to researchers as you tailor dissemination activities to meet the needs of specific user groups – such as rural residents with disabilities.

## Conclusion

Many features and strategies are apparent to researchers that are interested in developing or improving your outreach efforts targeting rural residents with disabilities.

As with any dissemination effort, the degree your resulting efficiency and effectiveness rests upon the "fit" between the:

- characteristics of the intended user group,
- perceived need for the content of the information shared,
- context through which the content of your information must be accessed, and
- media through which you distribute the content.

# Related Resources on Rural Issues

## Administration on Developmental Disabilities

**http://www.acf.dhhs.gov/programs/add/**

Ensures that individuals with developmental disabilities and their families participate in the design of and have access to culturally competent services, supports, and other assistance and opportunities that promotes independence, productivity, and integration and inclusion into the community.

## Association of Programs for Rural Independent Living (APRIL)

**http://april.umt.edu/**

APRIL is a national network of rural independent living centers, other programs, and individuals concerned with the unique aspects of rural independent living.

## Directory of Rural Assistive Technology Resources

**http://pasture.ecn.purdue.edu/ABE/Extension/BNG/plowshare22.html**

A listing of resources, services, agencies, and programs that serve farm and rural families with disabilities.

## Links to information about rural issues

**http://www.ilru.org/news/NewsLetter/June2000/RuralLinks.htm**

## National Association of Development Organizations (NADO)

**http://www.nado.org/links/index.html**

Resource links for training, information, and representation for regional development organizations serving small metropolitan and rural America

## National Association of Protection and Advocacy Systems (NAPAS)

**http://www.napas.org/**

NAPAS, the voluntary national membership association of protection & advocacy systems and client assistance programs,

## National Rural Development Partnership (NRDP)

**http://www.rurdev.usda.gov/nrdp/what.html**

NDRP works to strengthen rural America through collaborative partnerships. The NRDP brings together partners from local, state, tribal, and federal governments, as well as from the for-profit and nonprofit private sector.

## National Rural Health Association (NRHA)

**http://www.NRHArural.org/**

NRHA is a national membership organization, consisting of approximately 2000 members, whose mission is to improve the health and healthcare of rural Americans and to provide leadership on rural issues through advocacy, communications, education and research.

## Rural Education

**http://www.ael.org/eric/rural.htm**

ERIC Clearinghouse on Rural Education and Small Schools (ERIC-CRESS)

## Rural Health Care Links

**http://www.commerce.usask.ca/ faculty/backman/ruralsit.htm**

Listing of Canadian and International sites (including U.S.)

## Rural Information Center Health Service (RICHS)

**http://www.nal.usda.gov/ric/richs /index.html**

RICHS is a joint project of the Office of Rural Health Policy (ORHP), Department of Health and Human Services, and the National Agricultural Library (NAL), United States Department of Agriculture. Operating as part of NAL's Rural Information Center (RIC), RICHS collects and disseminates information on rural health issues.

## Rural Policy Research Institute (RUPRI)

**http://www.rupri.org/**

RUPRI provides objective analysis and facilitates public dialogue concerning the impacts of public policy on rural people and places.

## U. S. Census Bureau:

- **Selected Historical Decennial Census, Urban and Rural Definitions and Data**
  **http://www.census.gov/population/www/censusdata/ur-def.html**

- **Revised standards for defining metropolitan areas in the 1990s**
  **http://www.census.gov/population/www/estimates/mastand.html**

- **Census 2000 Urban and Rural Classification**
  **http://www.census.gov/geo/www/ua/ua_2k.html**

## Who's in the News

NCDDR staff members are on the lookout for popular and disability media pieces that present research funded by NIDRR.

In this issue, we share news items from the

- ***St. Petersburg Times***,
- ***Boston Globe***,
- ***HR Magazine***,
- ***Chicago Tribune***, and
- ***Atlanta Journal Constitution***.

Please let the NCDDR know when an item representing your NIDRR-funded project appears in the media. Call 1-800-266-1832, or send an email to **ncddr@sedl.org** and we will review it for Who's In The News. You may also use an online form: **http://www.ncddr.org/forms/submitnews.html**

***St. Petersburg Times Online*** posted an article in the Tech Times section entitled *Tech Able* on March 11, 2002. The article discusses accessibility to mainstream technology by people with disabilities, the progress to accessibility that is being made as awareness of needs grows, and how the technology developed for people with disabilities is becoming mainstream as the population ages. The article features two NIDRR-funded projects.

- Katherine Belknap, Project Director of ABLEDATA, agrees that technologies have become more mainstream, "One of the best examples is voice recognition software. It originally began as a way to make computers accessible for people who didn't have use of their hands." She notes that voice recognition software is a "critical tool" for many who work with computers. The ABLEDATA project maintains a Web site that contains information on assistive technology and rehabilitation equipment and, in addition, provides information, links, and resources to meet the special technology product needs of consumers and professionals. For further information contact **Katherine Belknap**, Project Director, at belknap@macroint.com or at **301-608-8998**.
- Geoff Freed, Project Manager at the CPB/WGBH National Center for Accessible Media (NCAM) at the WGBH Educational Foundation in Boston comments on the issue of Web accessibility. Although he believes that "Web sites are designed more sensibly" than they used to be, he feels that Web accessibility "is not as widespread as it needs to be." NCAM is a research and development facility dedicated to creating access solutions for existing and emerging media technologies. For further information, contact Geoff Freed at geoff_freed@wgbh.org or at 617-300-4223.

The article originally appeared in the technology section of the March 11 print edition of the **St. Petersburg Times**. The article was written by **Dave Gussow**, Personal Technology Editor at the St. Petersburg Times, who contacted the NIDRR-funded projects for information. When asked why he selected these two projects for information on technology and people with disabilities, Mr. Gussow responded, "I was aware of the National Center for Accessible Media beforehand, though it was also mentioned by at least one other person interviewed for the story. I found ABLEDATA while doing research on the Web and called." An online version of the article is available at **http://www.sptimes.com/2002/03/11/Technology/Tech_able.shtml**

URLs for Web version only:

**http://www.sptimes.com/**
St. Petersburg Times Online

**http://www.abledata.com/**
ABLEDATA

**http://ncam.wgbh.org/**
National Center for Accessible Media (NCAM)

The **Boston Globe** published an article in their Sunday "BostonWorks" section on November 11, 2001 entitled *Technologically Enabled*. The focus of the article is on how assistive devices have made it possible for individuals with disabilities to enter the work force, maintain quality employment, and increase their career opportunities. A recent announcement made by Rush Limbaugh, talk show host who has lost his ability to hear, exemplifies "technology's ability to help those with disabilities enter–and remain–in the work force." Limbaugh vows that he will find ways to continue to communicate in spite of his hearing loss. William Kiernan, Ph.D., Director of the Institute for Community Inclusion (ICI) notes, "His announcement is symbolic because, essentially, he has said his hearing loss will not seriously compromise his ability to work, and he is correct." The ICI identifies and supports effective practices that facilitate participation in all aspects of the community, including employment, for individuals with disabilities. Featured in the article are excerpts of positive experiences with assistive technology told by individuals with disabilities whom the ICI assisted on the job.

Dr. Kiernan is Principal Investigator of the NIDRR-funded RRTC on State Systems and Employment. The RRTC is a project of the Institute for Community Inclusion/UCE at Children's Hospital and the University of Massachusetts Boston. He is also a Research Associate in Medicine at Children's Hospital and Adjunct Professor in the Graduate College of Education at UMass Boston. He can be reached at **william.kiernan@tch.harvard.edu**

The article was written by **Diane E. Lewis**, a staff writer with the ***Boston Globe***. The reporter, who worked closely with ICI staff to develop the piece, was initially contacted by ICI staff. Previously identified as a journalist "who covered workplace/labor issues for the city's largest paper," the ICI staff made it a point to periodically submit press releases and workshop announcements to Ms. Lewis. This ongoing contact by ICI staff developed into an opportunity to pitch a story on "the technology spin on employment," a topic that Ms. Lewis was interested in pursuing.

For further information contact **Danielle Dreilinger**, Communications Specialist, at **danielle.dreilinger@tch.harvard.edu** or at **(617) 355-2211**. An online version of the article is available for a fee in the ***Boston Globe's*** archives at **http://www.boston.com/globe/search/**

URLs for Web version only:

**http://www.boston.com/globe/**
The Boston Globe

**http://www.childrenshospital.org/ici**
Institute for Community Inclusion

**http://www.childrenshospital.org/ici/rrtc/**
RRTC on State Systems and Employment

**http://www.childrenshospital.org/**
Children's Hospital

**http://www.umb.edu**
University of Massachusetts Boston

***HR Magazine***, an official publication of the Society for Human Resource Management (SHRM), published an article entitled *Enabling Safe Evacuations* in January, 2002. Written following the September 11 tragedy, the article focuses on emergency preparedness and safe evacuation planning. According to the article, "The Americans with Disabilities Act (ADA) requires employers to modify their policies and procedures to include people with disabilities. These requirements apply also to evacuation plans." The authors note that those responsible for devising new plans and procedures for the safe evacuation from buildings "need to ensure that their plans include everyone." Ten steps are featured in the article that can assist employers in implementing safe emergency evacuation procedures for all their employees, including individuals with disabilities.

The article was co-authored by Susanne Bruyère, Ph.D., Director of the Program on Employment and Disability at Cornell University and by William G. Stothers, Deputy Director of The Center for an Accessible Society. Following the events of September 11, The Center for an Accessible Society contacted Elaine Ostroff, founder of Adaptive Environments Center, and with her help contacted all the NIDRR Centers working on Universal Design, and over 80 other experts that work on safety and universal design issues for people with disabilities. Mr. Stothers gathered the resources and information on safe evacuation plans and emergency preparedness to help employers and human resource personnel meet the needs of employees with disabilities during emergencies.

To disseminate the information to the intended audience, the authors pitched their story to ***HR Magazine***, whose readership includes over 165,000 members of the Society for Human Resource Management, the "world's largest association devoted to human resource management." Previous work and contact with SHRM by Dr. Bruyère facilitated the publication of the article. An online version of the article is available at
**http://www.shrm.org/hrmagazine/archive/**

For further information, contact **William G. Stothers** at **wstothers@accessiblesociety.org** or **(619) 232-2727**, and **Dr. Susanne Bruyère** at **smb23@cornell.edu** or **(607) 255-7727**.

URLs for Web version only:

**http://www.shrm.org/hrmagazine/**
HR Magazine

**http://www.shrm.org**
Society for Human Resource Management

**http://www.accessiblesociety.org**
The Center for an Accessible Society

**http://www.ilr.cornell.edu/ped/**
Program on Employment and Disability

**http://www.adaptenv.org/**
Adaptive Environments Center

The ***Chicago Tribune*** published an article entitled *Accommodate ADA and Get on with Business* on January 9, 2002. The article reflects on the decade-long debate about what constitutes a disability under the Americans with Disabilities Act (ADA) and how this ongoing debate costs society in terms of delayed justice and litigation fees. Noted in the article is the fact that "smart" businesses have moved on and "accepted the spirit of the ADA", and thus have experienced "improved employee morale, reduced turnover, and savings on retraining costs by implementing progressive ADA programs." In addition, these businesses have discovered that making "reasonable accommodations" is, in fact, a cost-effective venture. Despite these insights, however, some companies still refrain from hiring individuals with disabilities because they fear the high costs for accommodations and ADA-related litigation.

Quoted in the article is Peter Blanck, Ph.D., J.D., and Director of the Law, Health Policy & Disability Center at the University of Iowa College of Law. Dr. Blanck, a leading ADA advocate who has researched ADA's impact on work places, comments on why some businesses resist the law. "It's a general maxim that the federal government is seen as intrusive and disruptive to an employer's judgment," he says. "Some resist [embracing the ADA] even if it doesn't make a bit of difference to their cost."

Dr. Blanck is Principal Investigator of two NIDRR-funded research projects–the RRTC on Workforce Investment and Employment Policy for Persons with Disabilities and I. T. (information technology) Works. In addition he is a Professor of Law, of Psychology, and of Occupational Medicine at the University of Iowa.

The article was written by **David Greising**, a Business Columnist with the ***Chicago Tribune***. An online version of the article is available for a fee in the ***Chicago Tribune's*** archive at
**http://pqasb.pqarchiver.com/chicagotribune/**

For further information, contact **Dr. Peter Blanck** at **peter-blanck@uiowa.edu** or at **(319) 335-9043**.

URLs for Web version only:

**http://www.chicagotribune.com/**
The Chicago Tribune

**http://www.its.uiowa.edu/law**
Law, Health Policy & Disability Center

**http://www.its.uiowa.edu/law/lhpdc/rrtc/index.html**
RRTC on Workforce Investment and Employment Policy for Persons with Disabilities

**http://www.uiowa.edu/**
University of Iowa

The ***Atlanta Journal-Constitution's*** Sunday edition published an article in their Personal Technology section entitled *Enabling The Disabled: Science Helping Restore Brain, Body Connections* on February 10, 2002. The article focuses on the use of current and future assistive technology to help people with disabilities, and the variable costs involved in purchasing the technology – "everything from off-the-shelf systems…that turn lights on and off wirelessly to one-of-a-kind technological marvels…" Although purchasing "off-the-shelf" technology involves minimal expense, "technological marvels" that now include brain-computer interfaces that will be able to restore useful muscle movement to persons with paralyzing injuries can be quite

*continued on page 18*

Who's in the News, *continued from page 17*

expensive. The author notes that finding the technology can sometimes be much easier than finding the funds to pay for it. Featured in the article is Michael Jones, Ph.D., Principal Investigator of the NIDRR-funded project Telerehabilitation to Support Assistive Technology at the Shepherd Center in Atlanta, Georgia. He agrees that technology to help people with disabilities can be expensive, especially when it comes to "new" technology.

Dr. Jones is working on new technology that will monitor a person's movement in a wheelchair by the use of sensors and audible warnings. He states that for persons in wheelchairs, periodic movement is essential to avoid the development of pressure ulcers. Acknowledging that the expense of new technology can be quite a burden for persons with disabilities, he believes that returning a person to a productive life is important and that all of us should be concerned with the expense of assistive technology since its use is also something to be considered by aging persons. Jones states, "Whether we are talking about doorways or streets or buildings that are more accessible, it's an issue that all of us will confront sooner or later."

The article was written by **Bill Husted**, Personal Technology editor, of the ***Atlanta Journal-Constitution***. Mr. Husted contacted the Shepherd Center for information on his story idea. Over the past years, the Shepherd Center's media relations manager has actively marketed story ideas to Mr. Husted, and as a result, he is familiar with the Center's work in this area. An online version of the article is available for purchase in the ***Atlanta Journal-Constitution's*** Archives.

Two other NIDRR-funded projects are currently administered by the Shepherd Center. These include the *Georgia Regional Spinal Cord Injury Care System* and *Aging after Spinal Cord Injury: Three Decades of Longitudinal Research.*

For further information, contact **Kim Lathbury**, Shepherd Center Media Relations Manager, at **Kim_Lathbury@shepherd.org** or **(404) 350-7708**.

URLs for Web version only:

**http://www.ajc.com/**
Atlanta Journal-Constitution

**http://www.shepherd.org/**
Shepherd Center

## NIDRR Grantee and Staff Recognition

The NCDDR continues to share the recognition given to NIDRR-funded researchers and their staff. All grantees are encouraged to send this information to the NCDDR for future issues. Email **ncddr@sedl.org**, call **1-800-266-1832**, or use the online form available on the NCDDR Web site: **http://www.ncddr.org/forms/submitrecog.html**

The American Association for Psychosocial Rehabilitation (AAPR) has awarded the *2001 Alice Fordyce Public Service Award* to **William A. Anthony, Ph.D.**, Executive Director and founder of the Center for Psychiatric Rehabilitation (CPR), Sargent College of Health and Rehabilitation Sciences at Boston University. This award recognizes his lifelong work in the field of psychiatric rehabilitation as a researcher, educator, and clinician. The award was presented to **Dr. Anthony** at the AAPR's 10th Annual United Nations Award Luncheon on March 13, 2002 in New York City. There are currently four NIDRR-funded projects housed at the CPR, including the **RRTC in Rehabilitation for Persons with Long-term Mental Illness**. For more information, contact **Dr. William Anthony** at **wanthony@bu.edu**

URLS for Web version only:

**http://www.bu.edu/sargent/**
Sargent College

**http://web.bu.edu/cpr/**
Center for Psychiatric Rehabilitation

**http://www.bu.edu/cpr/research/rtc2004/**
RRTC in Rehabilitation for Persons with Long-term Mental Illness

**Tom Seekins, Ph.D.**, Director of the **Research and Training Center on Rural Rehabilitation (RTC: Rural)**, University of Montana, was awarded the first *Earl Walden Award for Outstanding Achievement in Rural Advocacy*. The award was presented to Dr. Seekins at the Association of Programs for Rural Independent Living (APRIL) Seventh Annual National Conference on Rural Independent Living in Portland, Oregon, November 3-5, 2001.

The award has been established by APRIL and Independent Living Research Utilization (ILRU) at The Institute for Rehabilitation and Research (TIRR) in Houston, Texas, in honor of the late Earl Walden, long time colleague and friend to APRIL and ILRU. Walden was instrumental in assisting APRIL in its early days of growth. APRIL, a nonprofit organization, is a national network of rural independent living centers that focus on rural independent living issues. For more information on the award and APRIL, contact Linda Gonzales, Executive Director, at 330-678-7648 or visit their website at **http://april.umt.edu/**

For further information, contact **Diana Spas**, RTC: Rural Information Specialist at **gargoyle@selway.umt.edu** or call her at **(406) 243-5760**.

URLS for Web version only:

**http://ruralinstitute.umt.edu/rtcrural**
RTC on Rural Rehabilitation

**http://april.umt.edu/**
The Association of Programs for Rural Independent Living (APRIL)

**http://www.ilru.org/**
Independent Living Research Utilization (ILRU)

**http://www.tirr.org/**
The Institute for Rehabilitation and Research (TIRR)

**http://www.umt.edu/**
The University of Montana

Two University of Pittsburgh researchers were recognized as *2002 Health Care Heroes* by the Pittsburgh Business Times at a March 7, 2002 awards ceremony in Pittsburgh. **Michael L. Boninger, M.D.**, Director of the Center for Assistive Technology (CAT), University of Pittsburgh/UPMC Health System, was awarded the *Health Care Innovation and Research Award*, one of six *Health Care Hero*

*Award* categories. The *Lifetime Achievement Award* winner was **Dr. Clifford Brubaker**, Dean of the School of Health and Rehabilitation Sciences at Pitt. The annual awards are given in recognition of "outstanding people and organizations that are making significant strides in the local health care field."

**Dr. Boninger's** research and work at the CAT have helped establish the Center as a "leader and innovator in the assistive technology industry" and as "the world's premier clinic providing technology for people with disabilities." He is currently the Research Director for the University of Pittsburgh's Department of Physical Medicine and Rehabilitation and the Medical Director for the Human Engineering Research Laboratories (HERL). **Dr. Boninger** is Principal Investigator for two NIDRR-funded projects, the **University of Pittsburgh Model Center on Spinal Cord Injury** and **Collaboration on Upper Limb Pain in Spinal Cord Injury**. Contact Dr. Boninger: **mlboning@pitt.edu**

**Dr. Brubaker** is described by his colleagues "as an educator, community leader, inventor and creator of disciplines." For over thirty years he has been involved in "refining a multidisciplinary educational and research model to address the full spectrum of rehabilitation. His educational model is now setting the standard for rehabilitation training programs throughout the world. " He is currently Co-Principal Investigator for the NIDRR-funded **RERC on Wheeled Mobility**, and PI for the **Research Training in Rehabilitation Science with Special Emphasis on Disability Studies** project. Contact Dr. Brubaker: **ceb1+@pitt.edu**

Read these online articles, with free registration for the online Pittsburgh Business Times:

**http://www.bizjournals.com/pittsburgh/stories/2002/03/04/daily41.html**
Six local health care professionals recognized

**http://pittsburgh.bizjournals.com/pittsburgh/stories/2002/03/18/focus2.html**
Innovation and Research Award: Michael Boninger

**http://pittsburgh.bizjournals.com/pittsburgh/stories/2002/03/18/focus6.html**
Lifetime Achievement Award: Clifford Brubaker

URLS for Web version only:

**http://www.bizjournals.com/pittsburgh/**
Pittsburgh Business Times

**http://www.cat.pitt.edu/**
Center for Assistive Technology

**http://www.shrs.pitt.edu/**
School of Health and Rehabilitation Sciences

**http://www.herlpitt.org/**
Human Engineering Research Laboratories (HERL)

**http://www.upmc-sci.org/**
University of Pittsburgh Model Center on Spinal Cord Injury

**http://www.upmc.com/**
UPMC Health System

**Marian Minor, P.T., Ph.D.**, a researcher and principal investigator with the **Missouri Arthritis Rehabilitation Research and Training Center (MARRTC)**, was the recent recipient of the *Virginia P. Engalitcheff Award for Impact on Quality of Life*. The award was presented by the Arthritis Foundation during the foundation's National Meeting on November 17, 2001 in San Jose, California. The award recognizes "a specific achievement by an individual, organization, product or body of research that makes a dramatic impact on the quality of life for people with arthritis." **Dr. Minor's** extensive contributions both nationally and internationally in the form of research, publications, presentations, development of educational materials, and development of community-based exercise facilities have made a substantial impact on the lives of people with arthritis. **Dr. Minor**, a physical therapist, is an Associate Professor in the School of Health Professions at the University of Missouri-Columbia. See full story on the MARRTC Web site: **http://www.muhealth.org/~arthritis/spotlight/minor5.html**

**Dr. Minor** can be reached at **minorm@health.missouri.edu** or **(573) 882-1579.**

**Karen Smarr**, a senior research specialist with **MARRTC**, was named 2001 *Outstanding Graduate Student of the Year* by the Council of Counseling Psychology Training Programs (CCPTP) during an awards ceremony on August 24, 2001 at the national convention of the American Psychological Association in San Francisco. The CCPTP is a non-profit organization that represents about 75 doctoral programs in counseling psychology. Presented by the CCPTP, the annual award is given based on "evidence of quality scholarly contributions, professional contributions, distinctiveness of such contributions and the student's promise as a future scholar-professional." **Ms. Smarr** is the first University of Missouri-Columbia student to receive the award since its inauguration in 1997. An online story is available at **http://www.muhealth.org/~arthritis/spotlight/smarr2.html**
**Smarr** can be reached at **(573) 814-6000**, ext. 3679 or by email at **smarr.Karen@columbia-mo.va.gov**

For more information on MARRTC items contact **Dianna Borsi O'Brien**, MARRTC Senior Information Specialist, at **obriendi@missouri.edu** or **(573) 882-2914**.

URLS for Web version only:

**http://www.muhealth.org/~arthritis/index.html**
Missouri Arthritis Rehabilitation Research and Training Center (MARRTC)

**http://www.arthritis.org**
The Arthritis Foundation

**http://www.apa.org/**
The American Psychological Association

**http://www.lehigh.edu/ccptp/**
The Council of Counseling Psychology Training Programs

**http://www.missouri.edu/**
University of Missouri-Columbia

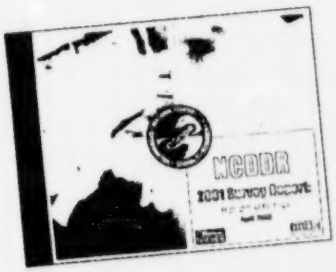
Access to Disability Research Information by Rural Consumers, *continued from page 7*

**Computer Access and Internet Use**

- Fifty-nine percent of rural consumers reported they had a computer at home.
- The Internet/Web was accessed most frequently at home (46%), followed by at work (34%), and at an Independent Living Center (31%).
- Of those rural consumers who did use the Internet/Web, 54 percent reported they used it to search for information/research. Forty-nine percent used it for email and 40 percent used it to communicate with a disability organization.
- Rural consumers reported slow Internet/Web connections (27%) and difficulty navigating Web pages due to unclear directions (27%) more often as barriers to using the Internet/Web than other barriers such as having limited access to a computer with Internet/Web (22%) or finding many inaccessible pages (15%).

## NCDDR-Produced Resources Currently Available

To obtain a free copy of any of these NCDDR Produced resources call 1-800-266-1832. Online copies are available by following the Web link provided at the end of the descriptions.

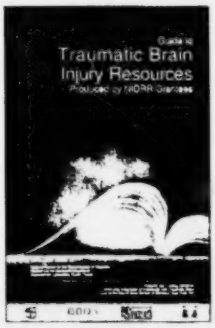



### NCDDR 2001 Survey Report

**Highlights of Findings**

In this report, major findings are highlighted based on consumer, stakeholder, and NIDRR grantee feedback. Findings from the annual NCDDR investigations are reported to provide D & U insights and suggestions that the NCDDR and other NIDRR grantees can most effectively and efficiently employ in conducting D & U to consumers and targeted groups.

Available Online:
**http://www.ncddr.org/du/products/survey2001/**




### Guide to Traumatic Brain Injury Resources

**Produced by NIDRR Grantees**

This guide was developed to assist researchers, professionals, and people with disabilities in locating research training materials related to traumatic brain injury and disabilities that were developed by programs funded by the NIDRR.

Available Online:
**http://www.ncddr.org/du/products/tbiguide/index.html**

### Web Sites You Can Use

This brochure serves as an information reference highlighting the projects funded by the National Institute on Disability and Rehabilitation Research in the Knowledge Dissemination and Utilization area. Information about each project includes: website address, major services provided, and contact information.

Available Online:
**http://www.ncddr.org/du/products/kdubrochuretxt.html**

## How To Contact The National Center for the Dissemination of Disability Research

**Call Us**
1-800-266-1832 or 512-476-6861 V/TT
8 A.M.–NOON and 1 P.M.–5 P.M. C.T.
Monday–Friday (except holidays) or
record a message 24 hr./day

**Explore Our Web Site**
http://www.ncddr.org/

**E-mail Us**
admin@ncddr.org

**Write Us**
National Center for the
Dissemination of Disability Research
Southwest Educational
Development Laboratory
211 East Seventh Street, Suite 400
Austin, Texas 78701-3281

**Visit Us**
Downtown Austin, Texas 4th floor,
Southwest Tower, Brazos at 7th St.
8 A.M.–NOON and 1 P.M.–5 P.M. C.T.
Monday–Friday (except holidays)

**Fax Us**
512-476-2286

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**An electronic version of *The Research Exchange*, Vol. 7, No. 2 is available on the Internet at URL <http://www.ncddr.org/du/researchexchange/>**

*The Research Exchange* is available in alternate formats upon request.

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NIDRR GRANTEE AND STAFF RECOGNITION ...15

This newsletter is available in alternate formats upon request.

SOUTHWEST EDUCATIONAL DEVELOPMENT LABORATORY
Building Knowledge to Support Learning

NIDRR

# Dissemination through the Public Media

## *A Word from the Director*

Dissemination is a process that is made up of five key components: content of message, context to access message, users targeted for use of the message, source putting forward the message, and the medium through which the message is shared. Effectively using "the media" requires that you have carefully considered the first four components of dissemination in formulating your decision about using a public information medium such as newspaper, radio, television or other public media outlets. It would seem reasonable that not all content lends itself to a public media or public information approach.

On the other hand, some content that may result from your research efforts may be best disseminated through the public media. The problem with this scenario, however, is that you do not control what the media will or will not do. Frequently, contacts from the media come when you are not expecting them. Your expertise is often a "drawing card" for journalists who want to verify some factual components of their story or to add related comments from an informed researcher source. Journalists' stories may not be exactly the story you wanted to tell, but your commentary and input must be fashioned around their story.

Effectively working with journalists to accomplish your goals and theirs is not an easy task. It goes without saying, however, that a story that incorporates your research findings in a popular media venue can be extremely impactful in reaching a mass audience. You should think of such stories as "opening the door" so that those who may have a current need can reach you. Clearly, having a quote or a portion of story devoted to your research will need to be complemented by you for the additional queries that can be expected to follow such coverage. Using innovative strategies such as a virtual press room or other electronic forums may also be beneficial additions to your dissemination options.

Examples are included in this issue of *The Research Exchange* that highlight how several NIDRR grantees have worked with the media in the past. This issue also presents expert advice in dealing with the media from The Center for an Accessible Society's NIDRR-funded Knowledge Dissemination and Utilization project. We hope this issue will stimulate some thoughts about the media that you may be able to apply in planning your dissemination. Ongoing technical assistance and information resources are also noted for your use.

John D. Westbrook, Ph.D.
Director, NCDDR

# Working With The Press

When research outcomes are ready to be shared in peer-reviewed journals and at professional conferences, the information can also be formatted for public dissemination and use. In this issue of *The Research Exchange*, NCDDR staff present topics related to working with the press, disseminating through other print media, and using the Web and electronic media for dissemination. Grantees share their perceptions of NIDRR researchers and their interaction with the press, and how collaboration with journalists can help with dissemination. Other topics include how disability is interpreted and portrayed in the news, news coverage versus publicity, and resources for working with the press.

Several NIDRR grantees' innovative uses of other media for dissemination are presented. Consumers and practitioners have a need to learn about research findings that can be applied to improve the lives of people with disabilities. The experiences presented here can serve as idea generators for NIDRR's researchers to look for creative and innovative ways to disseminate and facilitate the use of their outcomes by a range of audiences.

## Retrospective on NIDRR Research and the Media

**By Cynthia Jones**

The Center for an Accessible Society was funded by NIDRR in 1998 to pursue coverage of disability research and independent living issues by the national mainstream media. Earlier studies, including one by the NCDDR, found that people with disabilities, like everyone else, get most of their information from the mass popular media. So that's where we proposed to devote our efforts.

When we first started this project, we believed the hardest part would be trying to interest members of the media in disability-related issues research. Members of the media, like most people in society in general, don't want to think about disability issues. But equally as difficult has been engaging the research community in responding to the media. I often refer to our task as being a matchmaker between two unwilling partners.

We underestimated the level of distrust or fear of media and misrepresentation among

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## How Does the Press View and Report on Disability Topics?

Understanding how representatives of the media report and present disability issues is important for those who want to use media channels to get information out to those who can use it. Knowing how the media view disability can help NIDRR grantees understand how to best approach reporters and how to 'translate' research findings for easy use by the media.

The Center for an Accessible Society conducted a study on "News Coverage of Disability Issues" in 1998. Dr. Beth Haller, Associate Professor of Journalism at Towson University, served as media consultant and is the study's author. The study involved content analysis of every article and television segment with a disability focus that ran during October and November 1998 in the eight elite, agenda-setting newspapers, three news magazines and the four television networks: ABC, NBC, CBS, and CNN. The analysis included a total of

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## The "Virtual" Press Room

When reporters call, it is good to have on hand the answers to common questions they may have about your work, organization, and staff. If you mail out a Press Kit, you will provide answers to many questions before the call comes in. In today's world, journalists also conduct research via the Web. Most larger corporations and many organizations are providing information for journalists by way of an online or "Virtual" Press or News Rooms.

You can help reporters who visit your Web site to find what they are looking for by identifying an area developed especially for the Press. Gather pertinent facts, so reporters can instantly find information about your NIDRR-funded project(s), what your hot issues are, who the experts are on your staff, and how to contact them. This won't eliminate the need to keep "hard copy" information at hand for responding to a reporter, but can establish basic background information. You can't have all the information there is about your research on your Web site, nor would you want to, but helping prepare the reporter ahead of time will make your conversations more informative.

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The NCDDR (*The Research Exchange*, Volume 4, Number 3, 1999) and The Center for an Accessible Society have given information to NIDRR grantees on how to work with the popular press. In this issue, Cynthia Jones, Project Director and Principal Investigator of The Center for an Accessible Society, reports on The Center's past four years of grant activities to encourage coverage in the mainstream media of disability research and independent living topics.

How disability is interpreted and portrayed in the news is presented in a summary of a study conducted by Dr. Beth Haller of Towson University (Haller, 1999). Other articles present different ideas for effectively working with reporters: a focus on the difference between publicity and news coverage; ways to establish a relationship with an institution's Media or Public Affairs office; and how to develop an online press area for NIDRR grantees' Web sites. Dianna Borsi O'Brien, Senior Information Specialist, for the Missouri Arthritis Rehabilitation Research and Training Center (MARRTC), describes one RRTC's unique dissemination project that partners with their university's School of Journalism.

**The experiences presented here can serve as idea generators for NIDRR's researchers to look for creative and innovative ways to disseminate and facilitate the use of their outcomes by a range of audiences.**

## Where is your Media or Public Relations Office?

As a researcher, you may have limited time to contact the media in order to make research outcomes available to the public. However, if your NIDRR-funded project is housed at an institution of higher education or other established medical or research organization, there may be help you can turn to. A Media Relations, Public Relations, or Public Affairs office is an organizational unit that does just that, and they are there to help you. They have established media contacts, and will know which sources would be the best fit for your project or specific topic.

Establishing a relationship with your organization's Media Relations staff may be more practical than making direct contacts with the media, depending on your situation. The Media Relations office can serve as a liaison, and help ensure the information you have to share is in a format reporters can use.

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## Collaborative Dissemination Efforts

**By Dianna Borsi O'Brien**

*If a tree falls in a forest and there's no one there to hear it, does it make a sound?*

As in the forest, so it is in dissemination: the information is not very helpful if no one knows about it. That's the idea behind the Journalism Dissemination Project of the NIDRR-funded Missouri Arthritis Rehabilitation Research and Training Center (MARRTC). If no one knows what MARRTC does and how it can help, the research and efforts are less beneficial.

One of MARRTC's eight projects, the Journalism Dissemination Project is housed in the School of Journalism at the University of Missouri - Columbia. The Project's Principal Investigator (PI) is Robert A. Logan, a former professional journalist, who is now a professor of journalism and the director of the Science Journalism Center. Dianna Borsi O'Brien is Senior Information Specialist. The dissemination

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# MEDIA MATTERS:

# What's the Difference?

## News Coverage versus Publicity

You're planning a conference on an important topic -- long-term care reform, for example. You want disability advocates, researchers, and consumers to attend You want people to know about your conference, because you want people to attend.

Do you want publicity for your conference, or coverage of the issue? They're quite different things. Which is more important? Why? Which is harder?

Getting publicity about your event is an easier task. It's something you control completely. You prepare a flyer or letter; you mail it -- or email it -- to a set group of people on a mailing list. You might send notices to newsletters. You might even run an ad in targeted publications, such as professional journals or publications aimed at disabled consumers. But in any case, you decide -- and control -- the content. If you have planned ahead and done your homework, you may get your notice in many publications and your mailing of flyers may reach thousands of people directly, and many more through pass-along and word of mouth.

While publicity may meet your goal of filling your conference, it's limited in scope. It reaches only those whom you target -- at most, those few thousand people who have the time, resources and interest in attending.

Coverage, on the other hand, is a mass-media proposition. You reach many more people -- people who are unable to attend, but who are still interested in your ideas and information -- but you give up control. Still, what you lose in control you gain in widespread dissemination of information about your issue to (potentially) millions of people across the U.S. and beyond.

News media are generally not interested in publicizing an event in and of itself. But if your event is about a newsworthy issue, coverage will carry your information to millions of people. Public mass media -- daily newspapers, television and radio -- reach hundreds of thousands of people at a minimum; most reach many more. The national news media -- NBC, CBS, *USA Today*, *Time* magazine, *The New York Times*, shows on National Public Radio -- reach millions of people daily.

Receiving coverage of your event, and the issues it represents, means that you give up control. Reporters will likely interview you or others associated with your event -- but they will just as likely talk to others not associated with your program -- including those whose opinions and research differ from yours. If your topic is considered controversial, they may even interview those who disagree with your approach or analysis of the issue. You will have no approval over what finally appears in the media.

Even if this is the case, getting coverage of an issue allows you to reach far more people than mere publicity, and is a first step in getting your issue on the public agenda.

Media Matters No. 7
The Center for an Accessible Society
*Used with permission*

**MEDIA MATTERS**

This article is an example of Media Matters, a twice-monthly, brief e-mail of media tips from The Center for an Accessible Society. Media Matters provides helpful information, tips and strategies to make it easy for you, the researcher, to be a valued source for reporters. Examples of topics recently presented include understanding the reporter's mindset, how to serve information to the reporter, the "when and why" of using a news release, how to develop a news release and make sure it is read, and creating and maintaining a media list.

Current recipients of Media Matters are Principal Investigators of NIDRR-funded projects. The Center for an Accessible Society urges PIs to add to the list persons on their projects who are responsible for dissemination, or who have any interaction with someone from the media. If you would like to be added to the subscriber list, or to add someone from your shop, please contact **Mary Johnson: mjohnson@accessiblesociety.org**

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people in the research community. While NIDRR produces the best disability research available, its research community tends to be media-shy for a number of reasons.

First, and most important, is that there seems to be a larger potential downside than upside for researchers in dealing with media. Neither NIDRR nor academia give credit for mass media dissemination in the review or tenure process; what counts is peer-reviewed journals. So while this builds the knowledge base among the research community, it really doesn't address the needs of the population at large.

Second, researchers really do not want to be in the limelight. Many perceive that mass media attention will be harmful to their careers when they come up for the next cycle of review; that their research peers will think less of them if they have been in the news too often.

Third, there is a "we'll serve no research before its time" mentality. Unfortunately, some research actually gets stale waiting for its time. There is also a "culture clash" in this respect: media wants it now, and researchers would rather massage it for a longer time.

Fourth, even if a researcher would like to talk to the reporter, between the government and the university (or other organization's) vetting processes, the ability to actually "talk" becomes stilted. After four years, I find this happening in myself as well. I feel the impulse to stop short of the story or make my quotes too cautious and risk coming off as "canned."

And last, some researchers have had previous bad experiences with the media. There are a number of reasons for this, too. People talk differently than they write, and this is especially true in academia. Not many people actually talk like a research report is written.

I recently sent a transcript of an audiotape to someone who participated in a news briefing we did on the "Definitions of Disability." He wrote back jokingly about what he had said at the briefing. If I hadn't had the tape, he might very well have thought that I misquoted him. So when someone sees their quote in print, it doesn't seem to them to be what they actually remember saying – even though it is.

Research terminology is very technical and needs modification so the reporter can understand it and then convey it to the general public. This translation of research to common understanding takes time. Whose time is it? The reporter expects the researcher to be able to explain their work in easily understandable language. The researcher expects the reporter to spend time breaking down the concepts and learning and digesting his or her work.

Unlike the university setting, where people read and talk about a report and then think about it and re-write, the news cycle is very fast and usually doesn't allow this luxury. Reporters rarely have the ability to get back to people to have them "approve" their quotes. This perpetuates the cycle of not wanting to talk to the media because "the reporters never get it right."

Having said all this, we believe the risk is worth taking. If people who need to know what is being worked on and what progress is being made are to find out about advances, they are most likely going to find the information in the media.

Researchers must seize the opportunity to tell the story of their research to the media. Even if all of the details and qualifiers are not included, the gist of the story will be true and sometimes even compelling. It may not be entirely what we desire, but if consumers learn something that leads them to find help, then the NIDRR research team will have succeeded.

So what can be done? The Center's NIDRR-funded project has tried to allay these concerns by providing "Media Matters," an every other week e-letter of tips on dealing with the media. By giving grantees tools that provide strategies for dealing with the media and the interview situation, we help researchers exercise more control. By having an understanding of "inside the media world" they can see the other side of the keyboard, so to speak, and create a better working relationship.

We have also coached researchers before they have been in a media environment. A number of NIDRR-funded researchers are identified as experts on the Center's Web site. They know they may get calls at any time to answer a reporter's questions. We have helped draft responses to articles and given critical feedback to "better the odds" of getting in the newspaper.

But we also are working on the media side. Every week we send an e-letter for Journalists. This effort is to create interest in disability issues. We attend media meetings to talk about disability issues, to give a disability perspective on issues that are in the public domain, and generally try to interest reporters in NIDRR research.

Reporters easily understand race, gender, age, ethnicity, and religion, but when you talk Disability their eyes glaze over. So we have been working on media organizations to help them understand Disability as Diversity. We explain public transportation, education and employment issues, setting up a parallel to the race issues of the 50's.

We can pitch employment issues—which we have—over and over, but once they see disability as diversity, they get it. It's as if a light bulb is turned on.

Is it working? Well, we are getting over 20,000 visits a month to the Center's Web site **http://www.accessiblesociety.com/** We get calls from reporters who are honestly trying to understand the issues. Because of our work they have a better understanding of the context of the disability story before they call the researcher.

Does it always get in print or on the air? We wish. Between our efforts to educate the media and the research community; to translate the research; the reporter finding our Web site and calling us, then reaching the best contacts; their editor "not thinking it is really a story," and the morning news--there are many steps. And that does not take into account the impact of 9/11, Enron, and other breaking news.

The NIDRR research community is such a rich network. The depth of knowledge and contacts in so many fields is mind-boggling. Currently, however, the NIDRR universe is scattered across the firmament like so many loose, sparkling diamonds. I often think about the powerful influence that could result if the NIDRR grantee network perceived of itself as a true knowledge network, pulling together more, referring to one another more often and collaborating to make a bigger, stronger impact collectively than individually.

This is all about "branding." Think about the NIDRR name being used like a "Good Housekeeping Seal of Approval." Right now the NIDRR "brand" is not very well known or used effectively. We need to work together to develop strategies that can make the NIDRR "brand" stand out for all to take note, so that when you say, "I am a NIDRR researcher" people in the media will know what that means, just like they know NIH or NASA.

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256 printed stories. Because so little television network news focused on disability, Haller included the entire year of 1998, and still had only 34 stories that aired (Haller, 1999).

Following is a brief summary of Haller's most notable findings and recommendations, from The Center for an Accessible Society's overview of the report.

- Nearly 70 percent of the stories concerning disability referred to no identifiable source with a disability.
- In the list of sources used, "national disability organizations were largely missing" (The Center for an Accessible Society, n.d.)
- A majority of news stories dealt with education and special education issues, in part due to the time of year when school is in session across the country.
- Few news stories about disability issues included women with disabilities.
- People with disabilities or their families were most often sources in disability-related feature stories. In 10 percent of the stories, local disability organizations were cited as sources.

Several of the report's recommendations for improving representation of disability issues follow:

- The disability "side" of the story should be in every story that includes disability issues, not just the 30 percent of the articles that used people with disabilities as sources.
- There is obvious media and public interest in education issues. Disability and education spokespeople can work together to get correct information about these issues into the news.
- Disability organizations should actively pitch serious story ideas. For example, well before a major Supreme Court decision is handed down, disability organizations should show journalists the implications of the case in their local community. The earlier a source knowledgeable in disability issues can intervene, the stronger the disability focus is likely to be.
- In suggesting print stories, disability organizations need to respond to the current print media norms of 'featurizing' and localizing stories. People who want to know more about the issues in-depth, read newspapers and news magazines. People who make an effort to keep up with the news are the opinion leaders, so disability organizations need to get correct information about the issues into the major print news media.
- In terms of television, disability organizations should focus on getting more stories onto the evening news because it is the number one news source in the United States. They should also work on creating non stigmatizing sound bites that can get into disability-related stories.
- Disability organizations need to get the names of their expert sources into the hands of TV news producers and prominent print journalists. (The Center for an Accessible Society, n.d.)

Disability researchers should be viewed as experts for news media reporting on a disability issue. This study shows that many reporters in both print and television media have a limited understanding of disability issues and how to find reliable sources for their stories. NIDRR grantees should keep this in mind as they make contact with a media representative. If a researcher is contacted, they can make a positive impact by sharing important information in a way the average person can understand.

Dr. Haller is conducting a follow-up study in 2002 that should be completed early in 2003. The study will describe the current state of media reporting about disability issues, and will compare the results with the 1998 study.

*An overview and the full report of Dr. Haller's study are available on The Center for an Accessible Society's Web site:*

**http://www.accessiblesociety.org/topics/coverage/0799reportoverview.htm**

**http://www.accessiblesociety.org/topics/coverage/0799haller.htm**

# Examples of Virtual Press Rooms

**American Academy of Family Physicians**
**http://www.aafp.org/press.xml**

**American College of Rheumatology**
**http://www.rheumatology.org/press/index.asp**

**American Urological Association**
**http://www.auanet.org/media_press/index.cfm**

**Intel**
**http://appzone.intel.com/pressroom/index.asp**

**Microsoft**
**http://www.microsoft.com/presspass/default.asp**

**Minitab**
**http://www.minitab.com/company/virtualpressroom/**

**Paradyne Corp.**
**http://www.paradyne.com/news_n_events/press_room/**

**Robert Wood Johnson University Hospital**
**http://www.rwjuh.edu/pressroom/**

**Verizon**
**http://newscenter.verizon.com/index.vtml**

### The "Virtual" Press Room

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What information should you have in your Virtual Press or News Room? In addition to basic identification of who you are, where you're located, and what you do, you can archive past press releases as well as articles or on-air segments that have appeared about your project or your research. It is helpful for a journalist to know what has already been printed or aired by someone else.

Make "Virtual Press Kits" available to introduce a new product, device, or important findings. If these materials are in a format that facilitate downloading and printing by the reporter, it will save on printing and mailing costs for "hard copy" press kit materials that may end up in a waste or recycle center.

**Make "Virtual Press Kits" available to introduce a new product, device, or important findings.**

Following are some suggested areas that could be included in a Web-based Virtual Press Room. Visiting Web sites and reviewing what is offered by others is a good way to identify what to make available in your own virtual Press Room. Remember to present information in a format useful to journalists--brief and succinct.

### Suggested Items for an Online "Virtual" Press Room

- Backgrounder — What is the organization's history?
- Who we are — What is the project's name, address, phone, email, Web site information, and who is the identified contact person?
- We're funded by the National Institute on Disability and Rehabilitation Research (NIDRR), of the Office of Special Education and Rehabilitative Services (OSERS), U.S. Department of Education. Reporters will want to know the source of your funding.
- What we do — What is the purpose and mission of the project and your research?
- Who the experts are Who are the experts on staff and what are their specific areas of expertise?
- How to contact the experts — Give accurate contact information. The experts on staff should be available and briefed in advance on how to respond if they are contacted by a reporter.
- Overview/facts about this field/topic — What is some basic information that will help the reporter understand important issues?
- Misconceptions about this field/topic — How can you help journalists avoid pitfalls?
- Our hot topics — What are the areas of major interest in this field?
- Story ideas for reporters — Based on the project's research findings, what stories need to be told and who is the contact?
- Story Archives — Give links to stories about this research or project that have appeared in various publications or on the air.
- Virtual Press Kits — What new products or other informational materials do you have to share with reporters?
- Press/News Releases — How many do you have? How are they organized?
- Current Press/News Releases — Less than six months or one year old.
- Press/News Release Archives — Classified by date and/or topics
- For More Information or Other Resources — What other sources can the reporter visit in order to consider the validity of the information offered?

# Resources for Developing Virtual Press Rooms and Press Kits

***A well-stocked online press room***
Mainsail Marketing Information, Inc., 11-29-00
**http://www.mainsail.com/mainmail/v5_pr.htm**

***Benefits of an online press room***
Hollis Thomases, Web Ad.vantage
**http://www.webadvantage.net/tip_archive.cfm?tip_id=194&&a=1**

***Create a press-friendly Web site***
Debbie Neville, © D. M. Freedman Co. 2000
Media Relations Central, a service mark of Community Media Workshop.
**http://www.newstips.org/MRC2/pressfriendly.html**

***How to build an online press center***
The Write Market, July 2002
**http://www.thewritemarket.com/press-center.shtml**

***Looking good online: Creating an electronic press kit***
Geneva J. King, 7-20-00
**http://www.channelseven.com/newsbeat/2000features/news20000720.shtml**

***Morphing of the digital press kit***
Len Stein, 9-14-00
**http://www.clickz.com/relation/onl_rel/article.php/829191**

***Should your site have an online press room?***
B. L. Ochman, President, whatsnextonline.com
**http://www.thewritemarket.com/press/ochman.htm**

***Virtual press box***
Jim Sterne, CIO.com, 9-01-98
**http://www.cio.com/archive.090198_customer.html**

### Where is your Media or Public Relations Office?

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The Media Relations staff can also assist you in preparing for an interview. In some cases you can do the interview at the Media office and not have to leave the campus, or have reporters come to your work setting.

If you have information for a Press or News Release, the staff can review it and assist you to get it in the best format for a positive reception by media representatives, as well as submit the release to contacts on their list.

Once you know your Media Relations staff, they will be able to keep your project in mind and contact you when an appropriate media opportunity arises. Most of these offices keep an "experts" list so they know whom to turn to when they receive a call for a commentary or other information. Although you may not want such calls on a daily basis, if you are able to respond in this type of situation, you may soon be seen as an expert. This will raise the perceived importance of your research and what you have to say.

NCDDR staff interviewed a representative of The University of Texas (UT) at Austin's Office of Public Affairs. One feature of their Web site is a Media Guide to University Experts. **http://www.utexas.edu/admin/opa/experts/index.html** This is a searchable electronic database and all faculty and researchers on campus can submit their names and areas of expertise. It is still in development, as UT researchers continue to 00000 add their names and contact information to the pool of experts.

The UT campus is large, and many of the individual departments and schools have their own Media/Public Relations offices. This model is found at other large institutions, and benefits researchers in that the staff is more informed about a specialized area. If you are not taking advantage of this type of service at your organization, call and make an appointment to see how the staff can help you get important research information out for public consumption and use.

### Collaborative Dissemination Efforts

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project's goals are "to increase arthritis news coverage and improve its content" (Young, 1999).

The Journalism Dissemination Project uses a resource available in any university setting — students — to round out the project staff. Employing students gives a tremendous diversity in skills. For example, at one time the staff included a medical reporter, a news reporter, a digital video reporter who developed animated images, a designer for the newsletter, and a webmaster.

A major component of the Dissemination Project is the MARRTC Web site: **http://www.muhealth.org/~arthritis/** Each of MARRTC's eight projects has always partnered with experts in the field — and with persons with arthritis or family members of adults and children with arthritis. The Dissemination Project's partners told us that persons who visit the MARRTC arthritis Web site wish to know more about (a) their specific form of arthritis and (b) seek general information on pain, treatment, and how to live better. These recommendations inspired a redesign of the MARRTC Web site, based on the type of arthritis, treatment, living well, and research.

Following is a description of some of the Dissemination Project's activities, including MARRTC's Web site.

#### Arthritis NewsBreak

MARRTC's newsletter, *Arthritis NewsBreak*, returned to print form in 2001 to reach persons who did not have Web access. In 2000, MARRTC's Director requested the Dissemination Project staff to review the need for a print newsletter. A mail survey asked former readers for the names and addresses of their favorite Web sites. Some former readers said they did not have access to the Internet and noted that they could not afford computers often because of high medication costs. A few months later, *NewsBreak* was back in print, in addition to the Web-based format. Today, the print version of the newsletter goes to about 1,000 readers and includes the highlights from the MARRTC Web site.

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#### MARRTC News Service

In recent years, the news media frequently has reported on new arthritis pain relievers. News was coming out faster than the MARRTC staff could track it. The solution was the MARRTC news service. On a daily basis, the Dissemination Project staff members search the Internet for news about arthritis and arthritis-related diseases. Each month more than two dozen headlines are posted from sources such as the UPI, Doctor's Guide, and InteliHealth. The top picks of the headline articles are summarized and included in the newsletter.

#### Online Calendar

Throughout the year, there are scores of arthritis-related events at the local, state and national level. To help readers keep up with the many activities in the world of arthritis, the Dissemination Project staff created an online calendar of *Upcoming Events*. The State of Missouri now uses the MARRTC calendar on its arthritis Web site.

#### News Releases about New Content

MARRTC's Farmers and Arthritis Project staff decided to develop a web page to show persons how to continue gardening despite their arthritis. The Farmers and Arthritis Project provided the content while the Dissemination Project worked with a graphic artist to create an interactive image for the page. The *Gardens For Every Body* page was unveiled by the Farmers and Arthritis Project at a university agricultural event, and the Dissemination Project sent out a news release to area media and other Web sites.

As a result of the changes outlined above, public interest in MARRTC's Web site increased from 40,000 hits per month more than 100,000. Email is sent to a growing list of people to notify them about the fresh Web content.

### Achievements of MARRTC Researchers

Articles posted on the Web site's *Spotlight* page tell visitors about the work conducted by MARRTC researchers. Included is a list of awards received by staff members. This information has been designed to help MARRTC staff respond to a federal reporting requirement to list the awards MARRTC personnel have received. This list is now maintained on an ongoing basis and used as a springboard for short articles about accolades received by MARRTC personnel and the MARRTC Web site.

Federal reporting also requires a list of products created by MARRTC researchers. *Publications by MARRTC Researchers* allows people to learn about the research MARRTC has completed. This page receives several hundred viewers a month.

### Collaboration with Other Projects

In the summer of 2001, a MARRTC researcher wanted to develop a Web-based curriculum to teach state vocational rehabilitation counselors about appropriate arthritis rehabilitation in the workplace. The project was part of a doctoral dissertation investigating what rehabilitation counselors know about arthritis and whether providing information would improve vocational rehabilitation outcomes.

On a tight deadline, the Dissemination Project helped the researcher find a Webmaster and designer, and offered guidance on collecting information for the Web site content. In November 2001, the Web site was unveiled and presented to state vocational rehabilitation counselors. Following the collection of research data, the vocational rehabilitation Web pages will be added to the MARRTC Web site, along with a series of articles about arthritis and the workplace.

### National Press Conferences

MARRTC has sponsored a number of press conferences at the National Press Club in Washington, D.C. Reporters are invited to hear from leading researchers in rehabilitation, depression, women's health and basic medicine. While attendance has been modest, the purpose of raising journalistic awareness about arthritis has been successful (Young, 1999).

### Upcoming MARRTC Event

The Dissemination Project's focus on assisting persons with arthritis and disabilities will culminate in a Town Meeting, to be held November 15, 2002, in Columbia, Missouri. The topic is *Arthritis & Disabilities: Does Society Do Enough, Spend Enough, Care Enough?* The Town Meeting will bring stakeholders together: physicians, people with arthritis, health-care plan administrators, public policy makers, and others. The outcome of the event will be consensus statements or recommendations to be given to government and non-governmental policy makers. With consensus statements drawn from persons who know the issues, policy makers may be able to develop policies that respond to the needs of people with arthritis and related disabilities.

### Every Opportunity Counts

The Dissemination Project is located across the hall from one of the busiest computer labs in the School of Journalism. When students ask to borrow a stapler or a pen, the Senior Information Specialist takes the opportunity to tell them they have to learn at least one fact about arthritis — usually, that arthritis is the leading cause of disability in America, according to the Centers for Disease Control and Prevention (CDC, 2002).

This information may not be important to students now, but one day they will be working as reporters or editors and a time may come when they will recall what they learned. Or, some of the students unfortunately may become one of 43 million Americans with arthritis, or have a family member who will develop this disease. Perhaps students will remember that research by MARRTC researcher Marian A. Minor has shown "that exercise at the conditioning level is beneficial not only at reducing pain but even at reducing swelling in the affected joints of people with rheumatoid arthritis" (National Center for Chronic Disease Control, 1999).

When that happens, MARRTC's Journalism Dissemination Project will continue its impact. PI Robert Logan described the issue of reaching reporters as "cultivating awareness so it is on the front burner in the minds of journalists instead of way back" (Young, 1999).

*Dianna Borsi O'Brien is Senior Information Specialist for the Missouri Arthritis Rehabilitation Research and Training Center (MARRTC). For more information, contact her: obriendi@missouri.edu or call 573-882-2914.*

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# Disseminating Through Other Print Media

Many NIDRR grantees are using innovative ways to disseminate information from their research findings in formats that people can use. It is not easy to identify appropriate target audiences, determine the best way to reach those audiences, and then how to structure the information to best meet the needs of the audience. The NCDDR staff solicits information about successful dissemination strategies to share with other grantees. What works in one setting may prove useful to grantees for structuring or refining similar efforts.

Examples of success reported by two NIDRR grantees are described in the following section. These examples reflect innovative techniques to heighten awareness and motivate the attention of journalists, as well as other audiences.

## Your Words, Our Image

The idea to develop guidelines for use of preferred terminology when writing about people with disabilities originated in the 1980's with the University of Kansas' first **Research and Training Center on Independent Living (RTC/IL)**, directed by Dr. Jim Budde. In 1984, a recommendation of a "Media Watch" campaign activity of the RTC resulted in sending letters to a variety of consumer-led organizations to ask them to identify preferred terminology related to people with disabilities. A small team at the RTC/IL reviewed the responses and developed the first *Guidelines for Reporting and Writing About People with Disabilities.*

The *Guidelines* "offers preferred language, style, and appropriate portrayals of people with disabilities," and reflects input from over 100 national disability groups. The suggested terminology has been adopted by the *Associated Press Stylebook*, American Psychological Association, American Association of Advancement of Science, and others. The *Guidelines* are updated every two to three years, discarding some terms and incorporating new ones according to changes in usage reported by the groups that are asked to review the terms.

The current (2001) version is the 6th Edition. The original *Guidelines* fit on a single page, while the 6th Edition fills a ten-page brochure. The cost for the brochure varies from fifty cents to one dollar, depending on the quantity ordered, and helps recover the cost of printing. Over 1,000,000 copies of the *Guidelines* have been distributed since 1984. Orders have been received for up to 10,000 brochures from, for example, some dioceses of the Catholic Church, Disney World, and governmental agencies. The *Guidelines* are often sent out free to reporters and some agencies for training purposes.

Following the development of the *Guidelines*, a poster (Your Words/Our Image) was created that lists negative and positive terminology in reference to people with disabilities. The 18" x 24" poster has been revised three or four times since 1984, with a major redesign carried out in 2001. A high-quality paper with some embossed copper and silver lettering helps draw positive attention to the message presented. The $15.00 cost of the poster (which includes shipping and handling) goes to defray the cost of printing.

The RTC/IL has received very positive feedback about the *Guidelines* and the poster over the years, which has encouraged the staff to continue to revise and produce them. Both products are described on and can be ordered from the Public Awareness and Media Portrayal page of the RTC/IL Web site: **http://rtcil.org/public.htm**

*For more information, contact Pam Willits, Administrative Assistant, Research & Training Center on Independent Living at the University of Kansas. pwillits@ku.edu (785)864-4095 Voice; (785)864-0706 TTY.*

## Land Mine Awareness

The **RERC on Improved Technology Access for Land Mine Survivors** is located at the Center for International Rehabilitation (CIR) in Chicago. With the assistance of Leo Burnett advertising company's Chicago office, two posters were developed to raise awareness about the issue of land mine deaths and injuries.

Each poster shows a young person, one a woman (the example presented in this issue) and the other, a man. The full body picture shows their missing limbs. The story of how they lost their legs to land mines--along with facts about the number of land mines still endangering people around the world--is printed in a shadow-like text, formatted to fill in an outline of where the missing leg would be. The posters are suitable for reproduction in magazines, and can be displayed on placards in public areas such as bus shelters, bus and train stations, as well as inside buses and trains. To date, Harpers, Atlantic Monthly, Bomb, and People magazines have generously donated space to run the poster images.

*For more information, contact CIR's Communications Manager, Anne Henry: ahenry@cirnetwork.org (312)926-0014*

# Using The Web and Electronic Media For Dissemination

In the past, the NCDDR has reviewed NIDRR grantees' Web sites for basic accessibility and content elements. According to *The Research Exchange* Volume 3, Number 1, **http://www.ncddr.org/du/researchexchange/v03n01/**, approximately 32% of grantees had Web sites in 1995-96. Today, some 75% of grantees have Web sites with information about their NIDRR-sponsored activities. Grantees have been encouraged to make their Web sites accessible, meeting the guidelines of the Web Accessibility Initiative (WAI) at level AA or higher, and considering all the requirements of Section 508. The NCDDR also pointed out, in *The Research Exchange* Volume 6,Number 3, **http://www.ncddr.org/du/researchexchange/v06n03/**, some issues related to copyright, privacy, and the need to update a site and indicate when it was updated. As the Web has grown and advanced, increased multimedia capabilities have brought new options for information sharing and new challenges for accessibility.

The three NIDRR grantees below share their experiences in using the Web and multimedia to interact with specific audiences, including people with disabilities, other researchers, and people interested in online educational opportunities.

## Communicating with Consumers via the World Wide Web

**By Mary Ellen Buning**

The **RERC on Wheeled Mobility** at the University of Pittsburgh takes its mission to communicate, disseminate research findings and provide technical assistance to its constituents very seriously. This constituency includes the almost 2 million individuals who use wheelchairs plus many others involved in prescribing, selling, servicing, transporting, manufacturing, funding and researching wheeled mobility technology.

It only seemed natural that the staff of the RERC who use current information technologies in so many aspects of managing the RERC—writing, teaching and training, quarterly and annual reporting, discussion lists, publications, etc.—would consider using it to interact more effectively with its constituents. Fortunately, the convergence of the RERC's vision of the World Wide Web (WWW) as a tool for doing this coincided with society's increased

**Communicating with Consumers via the World Wide Web** continued on page 12

## Technology Expands Educational Opportunities

**By Teri Blankenship**

The RRTC **on Workplace Supports** of Virginia Commonwealth University has developed a skilled infrastructure at the Center to provide quality education options to employers, rehabilitation professionals, government, educators, and people with disabilities, utilizing a variety of technology tools.

We currently offer **eLearning** opportunities and **satellite teleconferences**. Utilizing technology allows us to provide cost effective synchronous and asynchronous national and international training to professionals on various topics that impact the employment of people with disabilities. In addition, we offer Continuing Education Units (CEUs) and Certified Rehabilitation Counselor Credits (CRCs) for our trainings.

### eLearning

We have created a Web-based environment that gives our audience information that will

**Technology Expands Educational Opportunities** continued on page 13

## Check Rock and Roll: Interactive CD-ROM

**Check, Rock, and Roll**. For anyone using a wheelchair following a spinal cord injury (SCI), those words mean more than "let's boogie." It is important to check one's skin, rock in one's chair, and roll over in bed to ensure that blood is not cut off to tissues, leading to pressure sores or ulcers. An interactive CD-ROM called "Check, Rock & Roll" has been developed that uses video, pictures, and sound to teach consumers about pressure sores and how to avoid them.

Under the direction of Principal Investigator Graham H. Creasey, MD, the Northeast Ohio Regional Spinal Cord Injury System at the MetroHealth Center for Rehabilitation in Cleveland was funded for a project entitled **Pressure Ulcer Prevention by Interactive Learning (P.U.P.I.L.)**. This was a Field Initiated Project sponsored by NIDRR. Project staff developed the interactive CD-ROM to train people with spinal cord injuries who have been recently injured or who have returned to hospital with a pressure sore. The CD-ROM demonstrates how to look for the signs of a pressure sore (check), the importance of shifting weight in the wheelchair every 15 minutes (rock), and the

**Check Rock and Roll: Interactive CD-ROM** continued on page 13



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**Communicating with Consumers via the World Wide Web**
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interest in the Internet. In the 2000 U.S. Census, data suggest more than 40 percent of all households have access to the WWW. Even those without access at home can expect to find it at their public library or workplace. This convergence has allowed us to use the power of the Internet and its tools to support interaction with new, and more distant constituents.

### Brief history of WheelchairNet http://www.wheelchairnet.org

WheelchairNet has been online since June 1999. The concept of WheelchairNet was born in the imagination of Dr. Douglas Hobson who saw the potential of the WWW to link together diverse and far-flung people who share a common interest: getting the most out of wheelchair technology. Doug has a strong reputation for his interest in consumers in all phases of the Assistive Technology service delivery process. WheelchairNet was founded on the concept of a "virtual community". . . a community that exists only in Cyberspace. Virtual communities have developed around travel, aging, sports and hobbies. These communities are based on a common interest in a topic and provide a place where people can learn, socialize, and work toward common goals.

We made an early decision that if the site was to be seen as consumer-friendly, it would have to accommodate slow computers and novice users from many backgrounds. First, we decided on a consistent page layout. Each page offers a way to go to other sections or back to the starting place as well as a link to searching and a site map that shows an outline of the site. Pages are largely text, which allows a screen synthesizer to read pages to the user. We also paid special attention to keeping page-size small so that those with slower connections would not have long waits as pages loaded. Each page has a date and a phone number. It is amazing how often someone will call on the phone to ask a specific question or to get clarification. We feel that this action creates accountability and lets people know that we are real people... not virtual people... and we want to be responsive.

The site content today is largely the result of the efforts of Dr. Mary Ellen Buning, who completed her doctoral research by developing the site and exploring the effect of exposure to WheelchairNet on consumer decision-making. Joe Ruffing, graphic designer and Webmaster; Barbara Crane, MS, PT, seating and mobility expert; and Sandra Hubbard, MS, OTR/L, a research associate; have made significant contributions to the effort through site maintenance and continued site development.

### How do we do it?

Although a great deal of information about products, the service delivery process, research and community living resources is available on WheelchairNet, the heart of the community is probably in the discussion area. The discussion area creates an archive of questions and answers that continue to educate and inform long after the original question was asked.

A visit to this section of the site at **http://www.wheelchairnet.org/cgi-bin/webx/** demonstrates that people use the site for a number of things. Some merely want to introduce themselves and make their experience with using a wheelchair known to others. Others arrive with a burning question on topics that include:

- What experiences have others had with this model of wheelchair I am considering?
- What is the best way for me as a school therapist to advise the bus driver to tie down wheelchairs that have tilt-in-space features?
- How do I get my landlord to help me add accessibility features to my apartment?
- What options do I have for pushing a child in a stroller and my child who uses a wheelchair?
- What unmet needs do wheelchair users have when using their chair? Are there features you wish were there but are not?

The range of these questions shows that WheelchairNet's users come from many groups. This communication link between these groups that don't normally have a chance to communicate—users, manufacturers, clinicians, funding sources, and researchers—has already created opportunity for community members to help each other by lending support, contributing information, sharing experiences and identifying solutions. Although the pace of the discussion ebbs and flows, the RERC staff makes an effort to answer all questions knowing that others will come along later with similar questions or issues and find some help there.

We know that the logistics of using our discussion software has, at certain times, been problematic for some users. What is easy to understand for one user may seem very complicated to another. The discussion area Sysop (System Operator) has the option of transferring questions or "topical threads" from locations where they are originally posted to areas where they can reside with similar questions. The Search feature on the discussion area makes it possible to search on words like "baby" or "tires" or "design" and find all the messages that contain those topics. In addition, users can subscribe to the discussions that interest them and are notified every time someone adds a message on their topic of interest. As more people gain experience on the Internet, the level of common knowledge about how to use discussion software seems to be increasing.

### Are we a virtual community?

Our RERC is part of a graduate program, and the students in the program are often experienced professionals who are able to lend their assistance in answering questions on the site. There has been funding to hire summer interns or student researchers who have worked on the site as part of an assistantship. Faculty members are often helpful in answering questions that are highly technical or which touch on areas of their research interest or expertise.

Since the Web site has yielded such positive feedback from RERC constituents, individuals in our academic and research programs have been willing to make the effort to answer questions. Best yet, the community of professionals, consumers, students and researchers out there in "cyberspace" step in to answer or respond when they see a place where they can contribute. It is perhaps this experience of having persons not connected with our RERC responding to questions that makes me believe that WheelchairNet has become the virtual community we envisioned.

*Mary Ellen Buning, PhD, OTR/L, ATP, is Assistant Professor, Department of Rehabilitation Science and Technology, University of Pittsburgh.*

*Dr. Buning is also Coordinator of Education and Dissemination for the RERC on Wheelchair Transportation Safety and continues Web site development for the RERC on Wheeled Mobility's WheelchairNet site.*

*Contact her at 412-383-6793 or mbuning@pitt.edu*

### Technology Expands Educational Opportunities

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help them "work smarter." Our eLearning options include several levels of knowledge experiences: our "Brown Bag Series," interactive live Webcasts, and online courses.

The *Brown Bag Series* located on our Web site is used for a quick overview, awareness, and opportunities to seek more in-depth information. Brown Bag sessions are 10–30 minute streamed video clips on disability and work-related issues with additional links and resources.

Topics to date include: Disability Management Best Practices, Investing in People Through Technology, Supported Employment Best Practices, Self Determination, Ticket to Work and Work Incentives Improvement Act, and Case Study on TBI and Work.

*Live Webcasts* are interactive live video and audio streamed over the Internet right to participants' desktops. The presentation is broadcast from Virginia Commonwealth University's Media Support Services' state-of-the-art distance education classroom. The Webcasts consist of 30 minutes of live lecture followed by 30 minutes of chatroom discussion with presenters. The chatroom offers real-time, scheduled access and interaction with our presenters. The participants can see, hear, and submit questions to the featured speaker. In addition, we provide technology that allows an "applet" box to be inserted in the Web page. The applet is a small program that performs the function of allowing the text to flow freely without buffering problems.

Our goal was to design the live Webcasts so that it would be easy to access using free software that most people already have on their browsers. Participants use RealOne Player, a free download, to view the Webcasts. We provide a live chat session with real-time translation and streaming text. Participants simply need to accept applets to view both of these features.

Resources and Web sites on the presenters' topics are listed for users who would like to research the topics in more depth. Following the Webcasts, the video and transcripts are archived for our users, and we ask participants to complete an online evaluation form.

*Online Webcourses* are comprehensive online training, usually consisting of six 2-week sessions. The courses use multi-media to deliver in-depth information on specific work and disability topics. Current courses include Supported Employment, and Benefits Planning Assistance and Outreach. Instructors provide feedback and support in chatrooms, discussion forums, and email throughout the length of the courses. Completion of the courses leads to certificates.

Approximately 1,500 people have participated in the RRTC's online offerings. To date, some 650 people have completed the Web-based Supported Employment Certificate Series.

#### Satellite Telecasts

Our telecasts are transmitted by satellite and viewed on a television monitor. To set up a down-link site the end-user must have a steerable satellite dish, receive C-Band transmission, and have the satellite coordinates. Most of our participants locate a receiving site such as a community college or university and market the training event to those interested, within their region.

The telecasts are two-hour events, which are broadcast from our Public Television Station. Satellite television is cost effective for distance education when offering high quality audio and video transmission for an unlimited number of national and international participants. There are usually 50-705 downlink sites for the satellite telecasts, and each of these sites may have 20-45 (or more) participants at their locations.

Our telecasts feature three to four experts on work and disability topics. The production is enhanced with visuals, video, case studies, and a packet of support materials for each participant. The live broadcasts are interactive by offering two to three ten-minute sessions for participants to call-in their questions to our panel of experts via a toll-free number that is provided. Following the broadcast, participants are asked to complete an evaluation form and to submit any questions to the RRTC that were not answered.

#### Future Outlook

We continually strive to improve our delivery methods, making our training accessible and easy to navigate. Our goal is to employ technology—whether it is a Webcast, online course, or teleconference—that is intuitive to the user, so that the logistics and design of the technology do not create barriers to the information and resources we are disseminating.

*Teri Blankenship, M.Ed. is Assistant Director of Instructional Technology for the RRTC on Workplace Supports.*

*For further information, contact her at (804)828-2197 or tcblanke@vcu.edu*

### Check Rock and Roll: Interactive CD-ROM

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need to turn over in bed every two hours (roll).

The CD-ROM allows a viewer to progress steadily through the program or select specific parts to view, including different suggestions for persons with paraplegia or quadriplegia. There are interactive sections that help users experience how a red spot on the skin may progress, and demonstrations of activities such as examining the skin and shifting weight. An index allows users to jump to a particular section.

Five individuals with SCI are featured on the CD-ROM, sharing their personal experiences and talking about how they prevent pressure sores. The video clips provide viewers with access to understanding how people's lives are affected, and are intended to increase involvement and motivation.

The CD-ROM was developed with the idea that it would be used at a hospital or other health care center, where patients could view the information on a computer and ask staff for help or clarification, if needed. It could also be used on a home computer.

The CD-ROM has been used successfully at MetroHealth, with positive feedback from both staff and patients. Using the interactive CD-ROM frees staff from giving repeated explanations and allows patients and family to be involved in active learning at their own pace and to review whatever they choose.

The authors are interested in conducting further research to evaluate the success of the CD-ROM in helping patients with SCI to prevent pressure sores, and in collaborative projects to expand and modify the information for other target groups and settings.

Copies of the CD-ROM are available for $20 to cover production, postage, and handling. To obtain a copy, contact Dr. Graham Creasey at Room H-604, MetroHealth Medical Center, 2500 MetroHealth Drive, Cleveland, Ohio 44109-1998. You may also call (216)778-5807.



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Members of the NCDDR staff are on the lookout for popular and disability media pieces that present research funded by NIDRR. In this issue, we share items from:

- ***Wired News online,***
- ***Public Radio International's Marketplace,***
- ***University of California–Davis Health System's Pulse Medical Television.***

Please let us know when an item representing your NIDRR-funded project appears in the media. Call us, 1-800-266-1832, or send email to **ncddr@sedl.org** and we will review the item for Who's in the News. You may also use an online form: **http://www.ncddr.org/forms/submitnews.html**

Gregg Vanderheiden, Trace Center Director, was interviewed by ***Wired News*** for *A Wearable Aid for Special Kids*, published online, May 10, 2002. The article focused on the practical applications of wearable computers, developed by Xybernaut, for children with disabilities.

"Schools also must consider the cost of teacher training and maintenance. Whether kids could take the computers home -- or take the technology with them as they advance to higher grades -- are all important questions," said Vanderheiden.

The article was written by *Wired News* reporter, **Katie Dean**. She said that someone from the Center for Applied Special Technology (CAST) first referred her to Dr. Vanderheiden. Ms. Dean stated that she is always interested in writing about new research that falls into the realm of educational technology. Read the full article: **http://www.wired.com/news/school/0,1383,52148,00.html**

The Trace Center at the University of Wisconsin-Madison administers two NIDRR-funded Rehabilitation Research and Engineering Centers: the RERC on Information Technology Access and the RERC on Access to Telecommunications. For further information, contact **Nancy Gores**, Communications Manager, at **(608)236-2309** or email: **nagores@facstaff.wisc.edu**

***Marketplace: The International Magazine of Business and Finance***, included a sound bite from Dr. Peter Blanck, Director of the University of Iowa's Law, Health Policy & Disability Center on Monday, April 29, 2002.

**John Dimsdale** presented a report on the Supreme Court ruling that employees with disabilities are not necessarily entitled to jobs or work benefits ahead of workers with more seniority. Dimsdale said "With today's 5 to 4 decision, the Court once again limits the reach of the 12-year-old Americans with Disabilities Act." He noted that "So far, the Supreme Court has sided with companies over workers."

Dr. Blanck, who studies the implementation of the ADA, commented "There have been a string of decisions limiting the access to the law by public employees, by people who have mitigated their impairments, by people with certain sorts of impairments -- carpal tunnel syndrome, for example."

*Marketplace* is produced in Los Angeles by *Minnesota Public Radio* in association with the University of Southern California and is distributed nationwide by *Public Radio International*, based in Minneapolis, Minnesota. The complete April 29 report from John Dimsdale is available from the Marketplace News Archives: **http://marketplace.org/shows/2002/04/29_mpp.html**

Dr. Blanck, Charles M. & Marion Kierscht Professor of Law, is Principal Investigator for two NIDRR-funded projects, the RRTC on Workforce Investment and Employment Policy for Persons with Disabilities, and a Disability and Rehabilitation Research Project, I.T. Works. He is often contacted by the press for comment. Dr. Blanck is listed as an "Expert Source" on The Center for an Accessible Society's Web site: **http://www.accessiblesociety.org/topics/ada/echazabal1.htm#adaexperts**

James L. Schmeling, Associate Director of the Law, Health Policy & Disability Center, noted that commentary opens the way to recognition as an expert source. "But the best approach to becoming a resource is to first become an expert in the area, then, to begin giving comment to national news sources."

Schmeling continued "This is the approach we take here. We issue press releases from the University of Iowa's public relations office for any major publication or event, and the press office distributes them to Iowa news sources. These are often picked up by national news sources. If a Center is located at a University, I would encourage them to take advantage of their news office." For more information, contact **James Schmeling**: **(319)335-8458** or **James-Schmeling@uiowa.edu**

Staff members of the RRTC in Neuromuscular Diseases and their research were featured in a segment of ***Pulse***, the University of California–Davis Medical Center's Emmy award-winning health magazine show. *Pulse* airs weekly in 90 of the top 100 television markets in America, and features up-to-date news about health and medicine. Living with a Neuromuscular Disease: Quality of Life aired on January 27, 2002, and features Nancy K. Seyden and Ted Abresch. Seyden is an RRTC Research Associate who was diagnosed with a neuromuscular disease at the age of 12. She has worked at UC Davis for 25 years. Abresch, RRTC Research Director, and Seyden carried out research on quality of life for people with neuromuscular diseases through interviews and surveys.

This segment shows how people with a neuromuscular disease view their quality of life positively by focusing on what they can do, not what they cannot.

The research found that in many areas, people with or without neuromuscular diseases reported similar satisfaction with the quality of their lives.

A lack of available information was another research finding, and the *Resource Guide on Disabilities* is a print and Web-based RRTC product to provide basic information about a range of disabilities, not just neuromuscular diseases.

Also presented was Nancy Seyden's class for medical students: *Wellness in the Context of Disability: Enhancing Physicians' Knowledge About Those Who Live With Disabilities*. This originally attracted the interest of the *Pulse* staff, and they contacted her. She and Dr. Kathryn Devereaux, Training and Information Services Director, worked out what would "get the word out better" and the *Pulse* producer liked their ideas.

For this *Pulse* segment, some home videos of Nancy's wedding, bird watching in a nature preserve, and shopping at a Farmer's Market were utilized to illustrate her high quality of life as a woman with a severe disability.

The RRTC staff members also drew attention to the online lecture, disability resource guide, and to Nancy Seyden and the RRTC as expert resources for disability issues, and sources for future stories.

For more information, contact **Kathryn Devereaux: (530)752-9270** or **kdevereaux@ucdavis.edu**
Script for *Pulse* Neuromuscular Disease Segment 1311 (html or pdf formats)
**http://pulse.ucdavis.edu/scripts/01_02/neuromuscular_disease.html**

**http://pulse.ucdavis.edu/scripts/01_02/neuromuscular_disease.pdf**

The July 5, 2002 edition of ***The Washington Post*** described current census data in an article entitled "*U.S. Counts One in 12 Children As Disabled*" (page B01). Washington Post Staff Writer **D'Vera Cohn** presented figures from the 2000 Census that reflect an increase in the number of children with disabilities, ages 5-20. Some of the increase can be attributed to changes in definitions of disability, including conditions such as attention deficit disorder that were not recognized in past years. Improved medical care was also mentioned, along with living in poverty, as factors contributing to the greater number of children with disabilities.

As one source for the article, Ms. Cohn contacted Glenn T. Fujiura, Director of the Center on Emergent Disability at the University of Illinois at Chicago. Fujiura noted that although the reasons for the increase in the number of children with disabilities may not be clear, the results are. "More children are coming forward with needs and limitations that must be met," he said.

The full article is available in the *The Washington Post* Archives.

D'Vera Cohn, who writes regularly for *The Washington Post* on matters of demography, said she found Dr. Fujiura because he had published an article in a newsletter put out by the *Population Reference Bureau*, an organization she deals with frequently. When she contacted him, Dr. Fujiura "was quick to respond and quite helpful."

For more information, contact **Glen T. Fujiura**: **gfujiura@uic.edu.**

## NIDRR Grantee and Staff Recognition

The NCDDR continues to share the recognition given to NIDRR-funded researchers and staff. All grantees are encouraged to send this information to the NCDDR for future issues. Send email to **ncddr@sedl.org**, call **1-800-266-1832**, or use the online form available on the NCDDR Web site: **http://www.ncddr.org/forms/submitrecog.html**

**David R. Gater, Jr., MD, Ph.D.**, Co-Director of the **University of Michigan Model Spinal Cord Injury Care System**, was honored in February 2002.

Dr. Gater received ***Best Poster Presentation*** by a Career Development Awardee at the National Veterans Administration RR&D Meeting in Arlington, VA. He received the award on February 12, 2002, at the conference "Rehabilitation Research for the 21st Century: The New Challenge," sponsored by the Department of Veterans Affairs, Research and Development Office, Rehabilitation Research and Development Service.

On February 28, 2002, Dr. Gater received the ***Young Academician Award*** from the Association of Academic Physiatrists, at the Annual Conference held in Las Vegas, NV. Dr. Gater was honored "for excellence in teaching, research and academic administration."

For additional information, contact **David Gater** at **(734)936-7210** or **dgater@umich.edu**

**George Kraft, MD, MS**, Director and Principal Investigator of the **University of Washington's Multiple Sclerosis RTC**, received the ***Distinguished Academician*** award at the annual Association of Academic Physiatrists (AAP) conference in Las Vegas. Each year the award is presented to an AAP member "who has achieved distinction and peer recognition regionally or nationally by virtue of excellence as a teacher, researcher and/or administrator."

Dr. Kraft is professor of rehabilitation medicine, Director of the Western Multiple Sclerosis Center and Electrodiagnostic Medicine and co-director of the UW Medical Center Muscular Dystrophy Clinic. He has served as chief of staff at the UW Medical Center.

For more information, please contact **George Kraft**: **ghkraft@u.washington.edu**, **(206)543-7272** or **Carolyne Dollar**, Research Program Manager: **dollar@u.washington.edu**, **(206)221-5302**.

**David F. Apple, Jr., MD**, Principal Investigator for the **Georgia Regional Spinal Cord Injury Care System**, was honored as ***AAOS Humanitarian of the Year*** by the American Academy of Orthopaedic Surgeons (AAOS). Presented at the 69th annual conference in Dallas, the award recognized "his support of people with physical disabilities by providing care for their injures and advocating for their transition back to the community."

"Dr. Apple's efforts to incorporate rehabilitation as mainstream in the orthopaedic curriculum and in the orthopaedic life in our country have been unceasing and effective," said Angus McBryde, MD, professor, department of orthopaedic surgery at the University of South Carolina.

Dr. Apple will give a $5,000 award from AAOS to the Shepherd Center in Atlanta, where he serves as medical director. He left his private practice to work with the Shepherd family to develop the spinal cord injury rehabilitation center in 1975. For more information, please contact **Kim Lathbury**, Media Relations Manager, **(404)350-7708** or **kim_lathbury@shepherd.org**

The ***Harry J. Murphy Catalyst Award*** was presented to **Judy Brewer**, Director of the **Web Accessibility Initiative at the World Wide Web Consortium (W3C)**, during the CSUN Conference on Technology and People with Disabilities. The Conference was held March 18-23, 2002, in Los Angeles. Ms. Brewer is the second recipient of the award sponsored by the Trace

R&D Center, University of Wisconsin-Madison, "created to help identify, acknowledge, and honor those who bring people together and facilitate the efforts of others in the field of technology and disability."

This biennial award is presented at the annual conference that was founded by Dr. Harry J. Murphy. Dr. Murphy was the first recipient of the Catalyst Award. The CSUN Conference on Technology and People with Disabilities has become preeminent in its field, and is a meeting place for people from around the world who are interested in improving the lives of people with disabilities.

For more information, contact Judy Brewer: **jbrewer@w3.org** or **Nancy Gores**, Trace Center Communications Manager, at **(608)236-2309** or email: **nagores@facstaff.wisc.edu**

**Judi Rogers**, a mother with a disability, activist and author, has earned the nation's highest honor for community health leadership: the ***2002 Robert Wood Johnson Community Health Leadership Program Award***. Rogers is a staff member at Through the Looking Glass, a Berkeley, CA nonprofit organization that houses the NIDRR-funded **National Resource Center for Parents with Disabilities**. Rogers was selected among 463 nominees for this year's award. She will be honored at a ceremony on September 24, 2002 in Washington, D.C. where she will receive the $120,000 award -- $105,000 for program enhancement at Through the Looking Glass, and $15,000 as a personal award. Trained as an occupational therapist, Rogers specializes in developing adaptive babycare equipment as well as pregnancy and birthing issues for women with disabilities.

For more information, contact: **Megan Kirshbaum** or **Paul Preston**, **(800) 644-2666** or **(510) 848-1112.**

## Selected NCDDR-Produced Resources

To obtain a **free** copy of any of these NCDDR Produced resources call 1-800-266-1832. Online copies are available.

### NCDDR 2001 Survey Report
**Highlights of Findings**

In this report, major findings are highlighted based on consumer, stakeholder, and NIDRR grantee feedback. Findings from the annual NCDDR investigations are reported to provide D & U insights and suggestions that the NCDDR and other NIDRR grantees can most effectively and efficiently employ in conducting D & U to consumers and targeted groups.
Available Online: **http://www.ncddr.org/du/products/survey2001/**

### Guide to Traumatic Brain Injury Resources
**Produced by NIDRR Grantees**

This guide was developed to assist researchers, professionals, and people with disabilities in locating research training materials related to traumatic brain injury and disabilities that were developed by programs funded by the NIDRR.
Available Online: **http://www.ncddr.org/du/products/tbiguide/index.html**

### Web Sites You Can Use

This brochure serves as an information reference highlighting the projects funded by the National Institute on Disability and Rehabilitation Research in the Knowledge Dissemination and Utilization area. Information about each project includes: website address, major services provided, and contact information.
Available Online: **http://www.ncddr.org/du/products/kdubrochuretxt.html**

## How To Contact The National Center for the Dissemination of Disability Research

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*The Research Exchange* is available in alternate formats upon request.

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**Physicians Against Land Mines**
Member of the International Campaign to Ban Land Mines

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# Land Mine Awareness

The **RERC on Improved Technology Access for Land Mine Survivors** is located at the Center for International Rehabilitation (CIR) in Chicago. With the assistance of Leo Burnett advertising company's Chicago office, two posters were developed to raise awareness about the issue of land mine deaths and injuries.

Each poster shows a young person, one a woman (the example presented in this issue) and the other, a man. The full body picture shows their missing limbs. The story of how they lost their legs to land mines--along with facts about the number of land mines still endangering people around the world--is printed in a shadow-like text, formatted to fill in an outline of where the missing leg would be. The posters are suitable for reproduction in magazines, and can be displayed on placards in public areas such as bus shelters, bus and train stations, as well as inside buses and trains. To date, Harpers, Atlantic Monthly, Bomb, and People magazines have generously donated space to run the poster images.

*For more information, contact CIR's Communications Manager, Anne Henry: ahenry@cirnetwork.org (312)926-0014*

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Your words Our Image
This is the slogan
Professional communicators, educators, and human service providers are in a unique position to shape the public image of people with disabilities. The words and images they use can create an insensitive, negative portrayal or a straight-forward, positive view of people with disabilities.

# Don't Say...

# Do Say...

| Don't Say... | Do Say... |
|---|---|
| able-bodied | nondisabled |
| AIDS victim | person with AIDS |
| brain damaged | person with brain injury |
| crippled | person with a disability |
| dwarf or midget | person of short stature |
| epileptic | person with epilepsy |
| hyper sensitive | person with environmental illness |
| insane | psychiatric disability |
| mongoloid | has Down syndrome |
| paralyzed | has spinal cord injury |
| physically challenged | person with a disability |
| retarded | person with mental retardation |
| slow learner | has a learning disability |
| spastic | person with cerebral palsy |
| special children | children with disabilities |
| stroke victim | stroke survivor |
| suffers from MS | has MS |
| the blind | people who are blind or visually impaired |
| the deaf | people who are deaf or hearing impaired |
| victim of polio | had polio |
| wheelchair-bound/confined to a wheelchair | uses a wheelchair |
| yuppie flu | person with chronic fatigue syndrome |

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**Research and Training Center on Independent Living** • University of Kansas • 1000 Sunnyside Avenue, Room 4089 Dole • Lawrence, Kansas 66045-7555
Ph: 785-864-4095 • Fax: 785-864-5063 • TDD: 785-864-0706 • rtcil@ku.edu • http://www.rtcil.org

# Your Words, Our Image

The idea to develop guidelines for use of preferred terminology when writing about people with disabilities originated in the 1980's with the University of Kansas' first **Research and Training Center on Independent Living (RTC/IL)**, directed by Dr. Jim Budde. In 1984, a recommendation of a "Media Watch" campaign activity of the RTC resulted in sending letters to a variety of consumer-led organizations to ask them to identify preferred terminology related to people with disabilities. A small team at the RTC/IL reviewed the responses and developed the first *Guidelines for Reporting and Writing About People with Disabilities.*

The *Guidelines* "offers preferred language, style, and appropriate portrayals of people with disabilities," and reflects input from over 100 national disability groups. The suggested terminology has been adopted by the *Associated Press Stylebook*, American Psychological Association, American Association of Advancement of Science, and others. The *Guidelines* are updated every two to three years, discarding some terms and incorporating new ones according to changes in usage reported by the groups that are asked to review the terms.

The current (2001) version is the 6th Edition. The original *Guidelines* fit on a single page, while the 6th Edition fills a ten-page brochure. The cost for the brochure varies from fifty cents to one dollar, depending on the quantity ordered, and helps recover the cost of printing. Over 1,000,000 copies of the *Guidelines* have been distributed since 1984. Orders have been received for up to 10,000 brochures from, for example, some dioceses of the Catholic Church, Disney World, and governmental agencies. The *Guidelines* are often sent out free to reporters and some agencies for training purposes.

Following the development of the *Guidelines*, a poster (Your Words/Our Image) was created that lists negative and positive terminology in reference to people with disabilities. The 18" x 24" poster has been revised three or four times since 1984, with a major redesign carried out in 2001. A high-quality paper with some embossed copper and silver lettering helps draw positive attention to the message presented. The $15.00 cost of the poster (which includes shipping and handling) goes to defray the cost of printing.

The RTC/IL has received very positive feedback about the *Guidelines* and the poster over the years, which has encouraged the staff to continue to revise and produce them. Both products are described on and can be ordered from the Public Awareness and Media Portrayal page of the RTC/IL Web site:
**http://rtcil.org/public.htm**

*For more information, contact*
*Pam Willits, Administrative Assistant, Research & Training Center on Independent Living at the University of Kansas.*
*pwillits@ku.edu (785)864-4095 Voice; (785)864-0706 TTY.*

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